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**A bio-ecological case-study investigation into
outlooks on the development and learning of
young children with cerebral palsy**

by

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A thesis submitted in partial fulfillment of the requirements
for the degree of Doctor of Philosophy in Education

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ABBREVIATIONS

BERA	British Educational Research Association
CDS	Children with Disabilities Service
GP	General practitioner
GSCE	General Certificate for Secondary Education
IEP	Individual Education Plan
NVQ	National Vocational Qualification
PIMIS	Physical Impairment and Inclusion Service
PPCT	Person-process-context-time
SEN	Special educational needs
SEYS	Specialist Early Years Support
SPSS	Statistical Package for Social Sciences
SENCo	Special Educational Needs Co-ordinator
TA	Teaching assistant

DECLARATION

I hereby declare that this thesis is entirely my original work and has not been submitted for any higher degree in another university.

ABSTRACT

This research examined outlooks on early development and learning of young children with cerebral palsy. Using a research framework informed by Urie Bronfenbrenner's bio-ecological model of child development, which integrates scrutiny of 'person', 'process', 'context' and 'time,' in combination with an exploratory case-study design, the study focused on the perceptions of a range of stakeholders in a local authority in the West Midlands of England as well as the observed experiences of children themselves.

Research questions required examination of stakeholders' perspectives of the developmental and learning identities of these children, the contextual circumstances for their early educational support, the processes by which their progression was or should be pursued, and future aspirations held for them. The final research question related the revealed outlooks to children's own observed educational experiences. The wide-ranging review of literature highlighted differences in academic perspectives on child development and disability, also a complex national 'patchwork' of early intervention for disabled children in general and for those with cerebral palsy in particular.

The empirical study was pursued through questionnaire surveys of parents and practitioners, also interviews with support-service managers and with parents and practitioners of six target children who were subsequently observed in their early educational settings. Integration of quantitative and qualitative data enabled all research questions to be answered comprehensively and in depth.

Findings showed that stakeholders' outlooks on the identity of children with cerebral palsy, evident in discourse and observed practice, were medically, socially or pedagogically oriented. Provision for these children was found to be extensive, but diverse in nature, not simply in terms of the services used, but also in relation to practitioners' qualifications, experiences, levels of confidence and professional roles. A range of pedagogical processes was evident in the various contexts – differences related to use of space and equipment, adult support, opportunities for children's socialization and other features. In terms of future aspirations, largely positive views were held, together with concern about the child's acceptance in peer contexts, particular at times of transition.

Drawing from findings, the study argues for a more distinctive pedagogical identity for children with cerebral palsy, echoing the Vygotskian (1993) perspective of disabled children's development as a socio-culturally influenced, exceptional phenomenon. Their development and early education should be perceived and pursued as an all-encompassing entity, with focus on motivation, interest and independence and reflecting strengthened notions of upbringing and pedagogy. Practical implications include renewed academic and professional discourse, revitalized training for professionals and greater practical involvement of parents in early educational provision.

CHAPTER 1: INTRODUCTION

1.1 Origins

Nearly a quarter of a century ago I came from my home country, Hungary, to work in England. It was not my first employment-related trip to another country, or indeed my first visit to the UK – I had worked previously in Northern Ireland and Wales with individual families and small groups of disabled children. Most had previously been to the International Pető Institute in Budapest to take advantage of specialist educational provision called ‘conductive education’. This Institute was where I trained and practised as a ‘conductor’, as part of Hungarian state provision for children and adults with motor difficulties, including cerebral palsy.

On this particular trip to England, however, the assignment was more than to work with small groups of children or with individuals. It involved contributing to a collaboration between a British voluntary organization and the International Pető Institute to transfer ‘the science and skill of conductive education and especially the teaching thereof’ (Charity Commission, 2014) from Hungary to a new national environment, England. The project included both the development of services and the establishment of professional training for a first group of British conductors. It also meant substantial discussions on provision and in particular on pedagogy with British and Hungarian colleagues and with external professionals from the English context. The overall task was simple, but considerable: how to develop a ‘westernized’ version of conductive education, faithful to its values and approach but receptive to the needs of British children and families? How to do this with proper regard for – if not technically within – an English system of special educational needs?

I suspect that at that time I did not fully recognize the scope and challenge of this commitment. Penn (2000) has illustrated how education, including education of the disabled, is not a universal, but a highly context-specific endeavor. Transferring an educational approach from any country to another would be problematic, given differences in national and social environments. When the transfer was from east to west, from one side of the 'Iron Curtain' to another, the task was likely to be particularly complex and difficult.

Conductive education in Hungary reflected a closed political system and socialist values of collective thinking. A citizen's duty was more to the state and to a common good than to oneself, even though in reality the country's political and social context was more liberal than elsewhere in central and eastern Europe at the time. Within these values, as described by an influential Soviet pedagogue, Sukhomlinsky (translated by Cockerill, 2009), education is perceived as one in which the dialectical relationship between the child and others (parents, educators and other children) is the most important feature. Adults lead the child in this respect, but through moral personality more than through any particular pedagogical procedures: 'We educate first and foremost, not with this or that variety of methods or techniques, but through the influence of our own personality, of our individuality' (Cockerill, 2009, p7). In terms of nurturing young children, positive outcomes are only achieved through operational co-operation between school and family, initiated by the former and developed by those with understanding and experience of giving guidance.

In this way of thinking curriculum is a broad concept, including everything which contributes to the child's all-round development – of personality, physical health and hygiene, sense of social belonging, behaviour and interests. It includes also the means by which a child experiences, learns about and connects with the realities of everyday life (Bakonyi and Szabadi, 1971; Millei, 2011). This curricular perspective

results in an integrated system of education in which 'everything is important – the lessons, the development of diverse interests, and the interpersonal relationship between the students in the group' (Cockerill, 2009, p29). Humanistic, collective values are central: education should prepare the child for future social activity, study and work so in turn they can contribute to common good and growth of society. The child in this respect is seen as able to develop a sense of belonging to the community, with regard to and reliant on others, and acquisition of skills necessary to become an active and happy citizen (Millei, 2011).

Educational practice in Hungary, therefore, reflected humanistic views on potential and development (Millei, 2011). Concern was for 'nevelés' – upbringing or nurturing – as much as for 'tanítás' and 'oktatás' – teaching and education, with the first as much as the second seeking to create and form personality and character, together with motives and patterns of social response, in the young growing child. This was underpinned by a social pedagogy which incorporated concern to develop knowledge and understanding of the social and natural world, as well as for growth of energy, interest and a healthy outlook on life (Cockerill, 2009).

My own upbringing and conductive-education studies at the Pető Institute had indeed reflected such values, nurturing in me an overall professional belief that education could bring change to people's lives, and more specifically that disability, including motor disorder such as cerebral palsy, did not need to compromise possibilities for learning and personal growth (Hári, 1997b). With a strong pedagogical mindset and well-developed practice, the young English children with whom I was working therefore could and would benefit from the same kind of learning and motivation which was striven for and expected with their non-disabled peers.

However, the values underpinning this conviction needed to be transferred to the very different English social, cultural and educational context. This new context emphasized democratic and capitalist enterprise, rather than socialist humanism. It stressed personal responsibility for one's own efforts and those of the family to make a success of one's life, combined with expectations on public services to support and promote potential development. Values for education reflected those of a post-modern western system of education, as described by Ball (1993) and (1998) and Garratt (2003), more than the ethics of collective thinking. Education in England mirrored a much more individualistic approach, with a strong concern for personal achievement in a competitive educational system (Penn, 2000).

In this context, special education itself, as described by Florian and Linklater (2010), incorporated and still incorporates a degree of uncertainty about its practice, and in particular how to make best use of the child's development and learning potential in the presence of disability. The system was then and remains now not just 'multi-professional', but explicitly 'multi-disciplinary' (Sloper, 1999; Watson *et al*, 2002), incorporating not only educationalists but also a range of paramedical services, such as physiotherapy and speech and language therapy, these being of particular relevance to the children with motor disorders and their families with whom I was working. The English system also has influential technical and operational features, most notably a now long-standing, robust, but largely bureaucratic 'Ofsted' inspection system (Case *et al*, 2000). In relation to children with disabilities there are many extra formal administrative processes too, such as 'statementing' – the identification of a child's special educational needs and of the professional help required to address them – and 'annual reviews' which monitor this process, as set out in the official SEN Code of Practice (Department for Education, 1994; Department for Education and Skills, 2001), of which a new, third manifestation has recently been published and put into effect (Department for Education and Department for Health, 2014).

In comparison with the curriculum I was used to, curriculum in England seemed over-formalized, interested most of all in content, outcomes and monitoring, as evident in the particularly burdensome requirements of the time (Department for Education and Employment and School Curriculum and Assessment Authority, 1996). Bernstein (1993, pxxi) described the system as reflecting concern for 'performance and the graded child'; Broadfoot *et al.* (2000, p3) as a 'discourse rooted in a rationalist vocabulary of scientific measures – of standards and scales; of objective judgments and comparison'. Outlooks and priorities for pre-school curricula has reflected some similar features, with elements of formal school-based education – literacy, numeracy – and above all concern for 'standards' (Department for Education and Employment and School Curriculum and Assessment Authority, 1996; Department for Education and Skills, 2000; Department for Children, Families and Schools, 2008), taking educators away from thinking innovatively about how to influence and invigorate growth and development of children and how to engage parents in that process (Leach, 2011).

For children with motor disorders and their families, the multi-disciplinary English system of 'special educational needs' and its generalized curriculum may create particular challenges. What to teach a child who cannot roll, sit or use their hands, or who has difficulties with communication, mobility and self-help? Should educators tackle these aspects themselves, or leave them to 'experts' – the therapists – and concentrate on other things? Parents of some of the children with whom I was working had found themselves in an awkward position in this respect. While appreciating the time, attempts and often the expense of English professional efforts to help their children, they appeared also to sense that this was not rewarded by their child's appreciable developmental progress or a clear idea of how this could be achieved – indeed many turned to conductive education in a search for more positive outcomes (BBC, 1986; Read, 1991).

1.2 Identity

From an educational point of view, cerebral palsy, as a neurological condition is certainly not straightforward. Its varied primary manifestations, as well as the many ways in which individuals may experience difficulties in voluntary movement, co-ordination, mobility, communication, sensory and cognitive development as a result, is likely be paralleled with complex secondary implications which impede development and learning. For educational establishments, as Sutton (1999, p19) suggested, the condition demands 'some very hard learning and adaptations', especially if its impact is understood professionally not simply from a biological or neurological perspective, but also in relation to its social implications, as identified by Vygotsky (1993). In these terms barriers and challenges which a disabled child may experience do not derive specifically from the organic difficulty associated with cerebral palsy, but more from the child's inability to access social and cultural scenarios which would provide them with the experiences needed for independent growth and development. As parents soon discover, the condition therefore has significant consequences for upbringing or the nurturing of processes of socialization (Ákos and Ákos, 1991; Read, 2000; Hazut, 2010), involving matters of which educational professionals may be less aware or may little understand, and which might be easily overlooked in the practice of early-years settings and schools, particularly where this is generalized for all children.

Yet perceptions about the development and learning 'identity' of children with cerebral palsy as a distinct group has sustained the legacy of a medical view traceable to the 19th century when William John Little first described the condition (Bleck, 1975; Cogher *et al*, 1992). Support for these children in early life and for their families remains dominated in the English context by provision from therapists (McDowell, 2010; Clifton, 2010), focusing principally on how the impact of cerebral palsy may be compensated physiologically through professional input. While a general medical

orientation therefore remains, the identity of children with cerebral palsy as a specific group seems to have become much less distinct, especially when contrasted with children with other developmental disabilities, such as sensory impairments or specific learning difficulties, and more recently autism (as in Jones, 2002; Wall, 2004; Lewis and Norwich, 2005). The identity of children who are the focus of this study, those with cerebral palsy, have become much less visible, being almost always 'mixed in' and hidden under the crowded and very large umbrella of 'special educational needs' (SEN Policy Options Group, 2009).

This is not to underplay the many developments in social policy and practice in relation to disability in England in recent years. There has been a changing perception of disability in general (examined more closely in this study's literature review), together with closer legislative and community understanding of disabled people – children and adults – themselves. A plethora of policy frameworks (also examined in the literature review) has guided and informed growth in provision and changes in practice. Within this framework the roles of two social contexts – the family and educational settings – have increasingly been considered and strengthened.

The main platform for support – early intervention for disabled children and their families – has seen particular development in recent years (Russell, 2007). Services have become more extensive, inclusive and family-centred (Carpenter, 2007). This growth has been accompanied by the introduction of general national frameworks for early-years education (Qualifications and Curriculum Authority and Department for Education and Skills, 2000; 2002; Department for Children, Families and Schools, 2008; Department for Education, 2012a). Important aspects of such frameworks include the 'unique child', emphasizing individuality; requirements to create 'enabling environments', with due regard to children's play as the main route for learning; and the wish to strengthen 'positive relationships' amongst children, their families and

practitioners so as to provide interactive opportunity for development and learning. Parenting itself has also been given substantial momentum in recent and current policy, expressed, for instance, in Department for Education and Skills (2004), Department for Education (2011) and Department for Education, 2012b).

1.3 This study

Consideration of 'identity' brings this introductory discussion to the research undertaken here. The study is founded in the belief that, amid the complexity of general policy and practice for very young children, children with cerebral palsy are a group which deserves more focused attention, in particular because of concern for their social and educational inclusion and development. This study seeks a more socially and educationally explicit outlook on their early learning and development, one which may stimulate an academic and professional dialogue that supports their collective social and pedagogical distinctiveness. From this can emerge closer understanding of the ways in which their learning and development can be supported in natural community contexts, such as the family, early childcare and educational provision. Fresh perspectives are sought by examining, analysing and contrasting a range of outlooks, captured within a policy-and-practice context incorporating the experiences of parents and educational stakeholders, as well as children's own observed experiences. By exposing and interrogating these multiple values, attitudes, opinions and practices, the study seeks to contribute to closer understanding of the complexity of early educational intervention and upbringing for these children. It may also stimulate change in views about their support needs and influence the processes by which their early development and learning is considered and addressed in early-years educational practice.

1.4 Research questions

The study addresses the following research questions:

RQ1: How is the identity of young children with cerebral palsy in relation to their development and learning perceived by their parents, early-years practitioners and representatives of local-authority support services?

RQ2: How are the contexts in which support for their development and learning takes place viewed by these stakeholders?

RQ3: What are these stakeholders' perceptions of the processes by which development and learning of these children takes place?

RQ4: In relation to time, how are future priorities and possibilities for the development and learning of these children viewed by these stakeholders?

RQ5: How is this range of outlooks evident in observed practical interactions between children and practitioners?

1.5 Definitions

In this study's pursuit of understanding about how in this evolving policy-to-practice context the development and learning identity of children with cerebral palsy is perceived by key stakeholders, two specific concepts play an important role: pedagogy and upbringing. While the first notion, pedagogy and pedagogical thinking, has attracted increasing scholarly interest in the discourses of education (Simon,

1980; Daniels, 2001; Alexander, 2004), early-years education (Siraj-Blatchford *et al*, 2002; Papatheodorou, 2007; Leach, 2011), and inclusive education (Wedell, 2007; Norwich and Lewis, 2005; Florian and Black-Hawkins, 2011), the latter notion, upbringing, together with the values and approaches on which it is based, remains in the English context a more elusive concept.

1.5.1 Pedagogy

A frequently cited definition of pedagogy comes from Alexander's (2004, p11): '... the act of teaching together with its attendant discourse. It is what one needs to know and the skills one needs to command, in order to make and justify the many different kinds of decisions of which teaching is constituted.' Daniels (2001) relates the concept not only to social actions, but also to the effects of these actions on learners: 'Pedagogy should be construed as referring to forms of social practice which shape and form the cognitive, affective and moral developments of individuals' (p1). Leach and Moon's (1999) definition also focuses on what educators do, but incorporates the more profound idea that pedagogy is a 'view of mind, of learning and learners, of the kind of knowledge that is valued and above all by educational outcomes that are desired' (pp268-69). What both Daniels and Leach and Moon imply here is a 'mindset', an attitudinal stance in which expectations of and commitment to the child's development and learning, including the formation of his or her identity, personality and learning attributes, are evident as a vital, overarching addition to concern for formal contextual learning outcomes.

In relation to early-years practice Papatheodorou (2007) suggests that the notion of pedagogy is often confused or used interchangeably with teaching, learning, or even curriculum. Indeed, the outcomes of Siraj-Blatchford *et al.*'s (2002) study, which was influential in developing frameworks for the early years, associated pedagogy closely

with curriculum, suggesting that 'different early years practices are informed by different educational philosophies and values and by the different assumptions that are held about learning, child development, appropriate styles of instruction and curricula' (p28) – seemingly arguing for pedagogy as a contextual, rather than a universal phenomenon, one guided by curriculum priorities and objectives, rather than by a desire (as in Daniel's definition) for children's all-round development.

1.5.2 Upbringing

Vygotsky (1991, p31)'s seminal definition related pedagogy to the second concept, upbringing: '*Pedagogika – nauka o vospitanii deteyi*' – pedagogy is the science of the upbringing of children. Mirroring this view, Kraevskii (2002) and Smith (2013) delineated upbringing as a pedagogical task, one which exceeds the narrow transmission of knowledge, development of skills and experience required to accomplish the goals associated with post-modern educational systems. Kraevskii (2002) illustrated its more holistic orientation:

It is a goal-directed activity, because the educator has to set a definite goal for himself: to teach particular things, to inculcate particular qualities of personality (humanness, morality, independence, the ability to be creative, and so on' (p84).

This encompassing notion of upbringing brings us back to the outlook of Sukhomlinsky (in Cockerill, 2009) cited earlier, one which values children's all-round development, rather than a disproportionate interest in learning of skills – the latter according to Leach (2011) has 'sadly set up many children... to fail before they even start school' (p23).

Sukhomlinsky also saw upbringing as a future-oriented endeavour during which the child is prepared for imminent activity: school learning, work and social activity. This is

achieved by nurturing the child's 'inner need for human fellowship' (in Cockerill, 2009, p31); its platform is interactions between the developing child and others: parents, educators and other children, processes of 'coming to know, of discovering a human being, of experiencing wonder at the many facets and inexhaustibility of human nature' (p11).

This kind of all-encompassing, forward-looking and child-centred outlook has clear relevance to nurturing development and learning in young disabled children, including those with cerebral palsy. While there remains in much of the English discourse a lack of consensus about how pedagogy for special and inclusive education should be defined and implemented (Corbett, 2000; Lewis and Norwich, 2005; Wedell, 2007; Florian and Black-Hawkins, 2011), interrogation of the issues underpinning upbringing of these children may help understanding of how interpersonal relationships and interactions with adults – parents or educators – may enhance their all-round and holistic development (Wedell, 2007) and of how within their early-years education appropriate, wide-ranging and pedagogically sound attention might be given to promote and enhance their development and learning.

1.6 Structure and presentation

In this investigation research questions have been addressed using a combined-methods, exploratory case study. This has involved two questionnaire surveys, three sets of interviews and several empirical observations. Data collection was carried out between April 2011 and September 2012 in a local authority in the West Midlands of England.

The thesis itself has eleven chapters. Following this introduction, Chapter 2 provides an overview of Urie Bronfenbrenner's 'bio-ecological model' for conceptualization and study of child development. Particular elements of the model are interrogated and the ways in which its use informed the study are considered.

Chapter 3 offers a review of literature, structured and scrutinized by using the four elements of this bio-ecological framework. Perspectives on disability, in particular on the development and learning of young children with cerebral palsy, are examined, together with professional outlooks on the changing systems for special educational needs and expansion of early educational provision. Literature on approaches to support the development and learning of these children is interrogated and an overview produced of understandings relating to their longer-term prospects and support needs.

The methodology of the investigation is examined in Chapter 4. Research design and approach are presented and discussed, and issues of sampling, data gathering and analysis, as well strategies for strengthening the validity, reliability and trustworthiness of elements of the enquiry, are interrogated. The chapter also considers relevant ethical dilemmas, indicating how these were addressed, with particular attention given to the researcher's own role and influence within the study.

Subsequent chapters focus on findings emerging from collection and analysis of data. Chapters 5 and 6 present quantitative results from the two questionnaire surveys, one amongst parents, the other with practitioners. Chapters 7, 8 and 9 offer findings from the three sets of interviews: with local-authority personnel, with early-years practitioners, and with parents. Chapter 10 reports on results obtained from observation of children in early-years settings and during home-based activity with a professional.

The final chapter, Chapter 11, draws together all the findings in order to contemplate each research question in turn. Implications for development of professional discourse and practice and further research are scrutinized. This chapter also considers use of Bronfenbrenner's bio-ecological model, reflecting on its benefits and drawbacks for this research, including how problems associated with model were overcome, and for social investigation in general.

1.7 Terminology

In this study, the term 'young children' refers to infants and pre-school children aged from birth to five years old, considered by national directives such as Department for Education (2012a) to be in their 'Foundation' years. When reference is made to 'parents' of these children, this is understood to include mothers, fathers, foster parents or other legal guardians with sole or shared responsibility for parenting a child.

'Cerebral palsy' in this study implies a group of motor disabilities (Armstrong, 2007) with neurological causes arising before, during or shortly after birth (Lewitt, 2010; Parkes *et al*, 2001). The condition has various manifestations and impacts on many areas of development and learning, of which motor co-ordination is most prominent (Baxter and Rosenbaum, 2005; Tatlow, 2005). A range of secondary difficulties may also influence the child's development, learning, health and well-being (Tatlow, 2005).

The notion of 'early-years settings' represents the varied services offered to young children and their families (Gambaro *et al*, 2013). These are available as maintained and non-maintained, voluntary, mainstream, home- or setting-based early childcare and educational provision, with additional or special services available for disabled children (Department for Education and Skills and Department of Health, 2003).

'Practitioners' include a range of personnel working in these home-based or setting-based provisions, such as early-years teachers and those with the status of 'early-years practitioner' (Hadfield and Joplin, 2012), also conductors, educators specially trained to work with children with motor disorders such as cerebral palsy (Brown and Mikula-Toth, 1997). It also includes teaching assistants, also known as 'learning support assistants', specifically tasked with supporting children with additional needs (McVittie, 2005; Richards and Armstrong, 2008). Some of these practitioners fulfill the role of key worker as well (Greco *et al*, 2006; Elfer *et al*, 2011), not only dealing directly with the child, but also acting as coordinator between early-years setting, the child's family and other agencies.

1.8 Time scale

The study was conducted between 2008 and 2014. During this time the overall context of the research was affected by two principal factors: a worsening global economic climate, and the change in UK government in 2010 from New Labour to a coalition of the Conservative and Liberal Democrat parties. While political rhetoric in this situation continues to emphasize a commitment to meeting the needs of the most vulnerable groups (Veck, 2014), welfare reforms, including the radical restructuring of the SEN support system (Department for Education, 2011; Department for Education and Department for Health, 2014), paralleled with austerity measures such as changes in the benefit system for families and cut-backs in local-authority budgets to finance local support services, have inevitably and sharply increased the reality that disabled children are 'lacking the resources they need to engage in the kinds of normal social activities that other children take for granted' (The Children Society, 2011).

The slow, some might say sluggish, emergence of the coalition's new legislative programme for special educational needs means that the study remains to a certain extent framed by directives implemented by the previous government.

1.9 Conclusion

This introductory chapter has provided personal, professional and academic justification for the study. It has explained its focus and objectives and located the investigation within three particular notions: identity, pedagogy and upbringing. Research questions have been shared and an overview of the written study provided; terminology and time-scale have also been clarified. The study progresses now to examination of the analytical framework for the investigation, the 'bio-ecological model' proposed by Urie Bronfennbrenner, together with scrutiny of its role within this research.

CHAPTER 2: FRAMEWORK FOR INVESTIGATION

2.1 Introduction

The analytical framework that guided this study derived from Urie Bronfenbrenner's perspectives on child development and the ways in which this could be investigated. In particular, the model's potential to project the complexity of such development and the vital role of social interactions in children's lives was persuasive when making this choice.

2.2 Bronfenbrenner, child development and research

Urie Bronfenbrenner, a Russian-born American child psychologist, established from the 1970s a complex system of propositions about children's development with which he sought to influence social policy and the practice of childcare in the USA. He termed his original ideas 'ecological' (Bronfenbrenner, 1977; 1979); with further advancements these then became a 'bio-ecological' framework (Bronfenbrenner, 1995; Bronfenbrenner and Evans, 2000).

Bronfenbrenner composed his model in order to challenge the nature of knowledge emerging from traditional scientific research studies carried out with and about children, describing his work as a 'reaction to the restricted scope of most research then being conducted by development psychology' (1994, pp37-38). In place of the two conventional research approaches – the first of which he termed a 'rock' to symbolize studies conducted in unnatural, scientific environments, the second a 'soft place', signaling excessive naturalistic observations (1977, p513) – Bronfenbrenner

developed his own, much more intricate model, addressing what he saw as the limitations of understandings which could be derived from those two contrasting traditions.

2.2.1 Influences

Bronfenbrenner drew extensively on a range of earlier theories of 20th century developmental and behavioural psychology, especially those reflecting Russian traditions. He used the words of Leontiev (1964) to identify the contrast between perceptions in western and Soviet psychological research: 'It seems to me that American researchers are constantly seeking to explain how the child came to be what he is; we in the USSR are striving to discover not how the child came to be what he is, but how he can become what he not yet is' (in Bronfenbrenner, 1979, p40). Bronfenbrenner's perspectives indeed incorporate a forward momentum, seeking to elucidate the complex ways in which children's development and progression are constructed and may be enhanced.

These ideas drew in particular from the concepts of two psychologists: Kurt Lewin, a passionate follower of Gestalt psychology (Thomas, 1996), and the Russian psychologist, Lev Vygotsky. Two of Lewin's notions are evident in Bronfenbrenner's writings. The first is the idea that child development takes place in 'life spaces' or 'psychological fields' (Bronfenbrenner, 1979, p23). These are real-life social contexts that are particularly influential in shaping a child's growth, and the notion is evident in Bronfenbrenner's central concern for the role of social environment in children's development. The second is Lewin's idea of the young developing person as a whole integrated organism, whose growth brings about re-arrangements in his or her social relations and interactions with others (Thomas, 1996). Bronfenbrenner extended this

concept to a more complex synergy of a wide range of influences – biological, environmental and interpersonal.

Bronfenbrenner gained even greater inspiration from his understanding of Vygotsky's socio-cultural orientation and the interpretation of child rearing as a historically and culturally determined phenomenon (Vygotsky, 1993; Ageyev, 2003; Gindis, 2003). Vygotsky's influence can be directly observed in many of Bronfenbrenner's propositions, relating to the child as a biological entity, to the surroundings in which she or he grows up, and to the interactions which connect the young person with the social environment. Similarity can in particular be seen between Vygotsky's strong emphasis on the social and interactive nature of learning and development (Sutton, 1988; Moore, 2000; Daniels, 2001; Smidt, 2011) and Bronfenbrenner's extended interest in examining the contextual circumstances for child development (Thomas, 1996), ideas which led both theorists to recognition of the socially embedded nature of upbringing (Wong, 2001; Kozulin, 2003; Smidt, 2011). Consequently, both perceived development as the outcome of socially determined interpersonal relationships, termed by Vygotsky as 'dialogues' (Moore, 2000) and by Bronfenbrenner (1977; 1979) as 'interactions'. Both believed the child to be an active agent in these interpersonal connections, leading to increased social competence.

While acknowledging the importance of Lewin and Vygotsky in his thinking, Bronfenbrenner developed a system which was more substantial in terms of recognizing the complex and intricate nature of influences governing children's development. He explained these as 'extending far beyond the immediate situation directly affecting the developing person' (Bronfenbrenner, 1979, p7). Furthermore, he proposed his intricate conceptualization not only as a model for child development itself, but also as an operational framework for research. As a result two interwoven strands are evident in his bio-ecological approach: firstly, a model that conceptualizes

child development; secondly, a substantive research framework for investigating that development. Both are examined here.

2.2.2 Model for child development

The primary concern in Bronfenbrenner's evolving system of ideas was children and their development. He crafted his ideas on this process over time, placing increasing emphasis on the complexity of environmental and contextual influences. In early work he explicated its phenomenological nature (Bronfenbrenner, 1979) – the individual's growing capacity to perceive, interpret, respond to and subsequently assimilate developmental stimuli from the environment. In his perspective the ways by which the child makes sense of the environment underpin the means by which she or he shows growth or decline in capacities. Later, he extended these ideas and argued for child development as a time-bound, progressive process during which the child draws from both personal and environmental resources to respond to the expanding social settings of which she or he is a part (Bronfenbrenner and Evans, 2000).

Bronfenbrenner's conceptualization was not, therefore, about incremental stages or changes in capacity as in other developmental theories, nor about age-related levels or expectations for performance and achievement. Instead, acknowledging Vygotsky's beliefs, he stressed the developing child's increasing and changing social awareness and ability to interpret the perceived reality of social scenarios, either positively instigating and enhancing progression, or hindering and negating it. As Bronfenbrenner (1979) argued, the ecology of child development is 'a theory of environmental interconnections and their impact on the forces directly affecting psychological growth' (p8), forces always intertwined with particular social and physical environments, in his words, 'development-in-context' (p7).

2.2.3 Framework for research

As noted earlier, Bronfenbrenner regarded his conceptualization also as a research framework by which this development could be studied. Dismissing scientific enquiries which had uni-directional or deterministic outlooks, predominantly focused on the attributes of the developing child, he constructed instead an investigative framework which highlighted not simply the link between the child and her or his environment, but more significantly the nature of reciprocal interactions between the two.

This idea drew attention to the child's interpersonal relationships with others in various social environments, such as immediate and extended family and childcare settings. It also involved consideration of the influence of social contexts more distanced from the child and with whom the child did not necessarily have personal contact at all, such as community, health and social care arrangements, local outlooks on child rearing and even national policies on early-childhood provision. For Bronfenbrenner (1995), understanding about children's development could only be accomplished if features of these multiple-level settings were interrogated:

The ecology of human development is the scientific study of the progressive, mutual accommodation, throughout the life span, between a growing human organism and the changing immediate environments in which it lives, as this process is affected by relations obtaining within and between these immediate settings, as well as the large social contexts, both formal and informal, in which the settings are embedded Bronfenbrenner (1977, p514).

2.3 An ecological model

Bronfenbrenner set out the basic principles of his ideas in his early 'ecological' model, these remaining pertinent even as the model became more complex and all-embracing over time.

2.3.1 Systems

As shown, Bronfenbrenner argued that development of every child was stimulated and determined by a range of ecological environments. He defined these at various levels, determined mainly by their distance from the personal, day-to-day experiences of the child.

Microsystems

The first and most proximate were 'microsystems', defined as the 'complex of relations between the developing person and environment in an immediate setting containing the person' (1977, p514). The most crucial was the family, then childcare and educational settings – social places where relations between the child and 'significant others' were underpinned by regular shared times and some form of attachment. Interpersonal relationships within these microsystems permitted or indeed inhibited the child's engagement in setting-related social activities, bringing about development of some kind (Bronfenbrenner, 1995). In this way Bronfenbrenner emphasized Vygotsky's legacy of child growth as a socially constructed process. For research, he proposed a phenomenological approach to discovering and understanding 'perceptions, feelings, expectations, and intentions with respect to the situation in which they [the child and others] are located' (1979, p127).

Mesosystems

Bronfenbrenner's next ecological layer was termed as 'mesosystems', indicating a 'system of microsystems' (1993, p40). These interfaces did not involve the child, but incorporated interactions between others, such as parents, the broader family, childcare practitioners, teachers or other professionals with whom the child was

regularly engaged. Connective elements within these mesosystems derived from a shared interest in the child's well-being and upbringing. Research into this aspect should focus on the interface between micro-settings, the various manifestations of this interface, and the impact of interactions on the activities of individual microsystems.

Exosystems

The third and increasingly more distanced level in Bronfenbrenner's ecological system referred to settings with which the child had no explicit or active involvement, but in which events and activities indirectly influenced processes within the child's microsystems. These settings included parents' work and a family's social network, more formal agencies representing health, welfare and education, and even relevant national policies. These exosystems, according to Bronfenbrenner (1977), encompassed or impinged upon more immediate systems and therefore affected what happened within them.

Macrosystems

Finally, 'macrosystems', perhaps the least explicitly explained element of the model, encompassed the broadest social arrangements, related to but most distanced from the developing child. Bronfenbrenner (1995) included here society's outlooks and value systems about childhood and child rearing, and the ways in which these are evident in social, legal, economical, health and educational arrangements. He saw these systems as being informal and implicit, mainly evident in 'customs and practices of everyday life' (p26). Impact from these settings was filtered down, influencing perceptions of policy makers, professionals and parents. Subsequently, for Bronfenbrenner, macrosystems also encompassed societal priorities, expectations

and resources. This was clearly illustrated when changing historical or cultural conditions altered the ways in which parenting, education, community support and resources advanced or hindered the overall functioning of microsystems.

This, however, was not the only direction of influence. Bronfenbrenner (1977) also identified a 'bottom-up' process, whereby the developing child itself brings about change in micro, meso, exo and even macrosystems. For instance, the child's individual needs might bring about alterations in the family's routine, or in the practice of childcare or educational provision, or may even contribute to society's changing thinking and revisions at policy level.

Within this range of ecological influences, Bronfenbrenner stressed interconnectivity as a prominent feature. This was encapsulated in Bronfenbrenner's (1979, p3) frequently cited description of 'concentric, nested structures, each inside the next', suggesting that each systemic level contributed to a complex overall scheme. As a consequence, as Bronfenbrenner delineated, an ecological research study was much more intricate than the single-setting or laboratory focus of much formal enquiry, and bi-directional influences should, in Bronfenbrenner's view, form an important focus of enquiry at all levels.

2.3.2 Dyadic and other interactions

Within his systemic propositions about influences in a child's life, Bronfenbrenner devoted most scrutiny to the first and most immediate level: the microsystem. Crucial at this level were interpersonal relations, the most important of these being 'dyads', the young, developing child's interactions with another person, usually a parent. There were different types of such dyads: observational, joint-activity and primary, signaling different kinds of involvement by the child in shared pursuits with this other person.

When more people were involved, for instance both parents or others in a childcare or educational setting, he symbolized this (as he often tended to do) as a mathematical formula, 'N + 2' (Bronfenbrenner, 1979, p58).

For Bronfenbrenner (1979) dyadic and 'N + 2' interactions were the 'basic building block of the microsystem' (p56), as well as the 'most powerful environmental forces that instigate and influence ... development' (p45). Most imperative amongst them were primary dyads, those which continued to exist for the child when the other person was not present. When these occurred, they formed the highest level of interpersonal relationship: the 'developmental dyad' (1970, p60).

Bronfenbrenner examined extensively the developmental influences which derived from dyadic interactions, again mirroring and extending Vygotsky's theories. Amongst many propositions, he suggested the pertinence of 'reciprocity': 'What A does influences B and *visa versa*' (1979, p57). For the very young child this involved an uneven power distribution, with the child in a less instrumental position. Researchers could, however, seek to capture the 'gradual transfer of power' (1979, p57) from adult to child, as the child learnt and grew up. Drawing on Drillien (1963), Bronfenbrenner (1994) eventually concluded that these reciprocal processes were 'more powerful than those of the environmental contexts in which they occur' (p39). He postulated that where interfaces between child and adult, or indeed amongst children themselves, were under-applied, the child had untapped potential for development.

2.4 Towards a bio-ecological model

This strong early focus on environmental and social factors was incorporated within the formal ecological model in ideas of 'context' and inter-personal 'process'.

Bronfenbrenner's maturing perspectives were later complemented with growing concern for and recognition of the child's own attributes as a significant contributor to her or his development, this notion being summarized as 'person' and leading to an overall conceptualization: the 'person-process-context' model (1994, p38). This Bronfenbrenner saw as an 'integrated system' in which human beings functioned and 'where the various psychological domains interact with each other' (1995, p636). The model was also seen by Bronfenbrenner as providing a research design to guide simultaneous and integrated investigation of these three constituent elements.

This turn in his belief system prompted elevation of his model from 'ecological' to 'bio-ecological'. With a final addition of the dimension of 'time', the model was ultimately termed as PPCT – 'person-process-context-time'. It is worth now summarizing each of these bio-ecological elements.

2.4.1 Context

The notion of 'context' remained the predominant pillar of his bio-ecological system throughout its further development. The multi-level ecological environments described above were perceived as being concentrically wrapped around the child, making them similar for all children at a particular time within a particular society.

They were, however, transformed into more distinct and unique entities as they intertwined with other elements of the system, thus producing differentiated paths for development and learning for each and every child. These ecological 'niches' (Sontag, 1996; Aubrey *et al*, 2000) did not simply refer to the proximity of children to their social environments, nor only to the extent to which particular settings had direct or indirect influence on their lives, but also to the way in which members of these settings reciprocally responded to each other and how they instigated or influenced each

other's behaviour. The combination of heterogeneity and divergence emerged, therefore, from the nature of the relations of the child with others, their mutual interactions and their shared activities established and sustained over time.

2.4.2 Process

A further dimension of the bio-ecological model referred to the face-to-face interpersonal dyadic, or more complex 'proximal processes' between the child and others with whom he or she had mutual attachment. In particular, the duration, frequency, timing and intensity of such processes were seen to be instrumental in instigating and influencing development (Bronfenbrenner and Evans, 2000). They could, however, have either desired or negative effects, producing either 'competence' or 'dysfunction' (Bronfenbrenner and Evans, 2000, p118).

2.4.3 Person

Bronfenbrenner's model also encompassed the factors which the child brings, often congenitally, to his or her dyadic or multi-person activities. Bronfenbrenner (1993) termed these as 'personal stimulus characteristics' (p11). With this dimension Bronfenbrenner recognized the uniqueness of human beings, reflected in their abilities and temperaments. These dispositions were seen to be exposed during interactions and to produce highly differentiated developmental outcomes.

2.4.4 Time

The final piece in Bronfenbrenner's jigsaw of ideas involved 'change or consistency over time, not only within the person but also of the environment in which the person lives' (1994, p40). When applied to a bio-ecological investigation, this aspect involved

looking at the effects of person characteristics and the environment on a child's development, for instance within cross-generational relationships and a 'life course perspective' (1995, p641).

2.5 Application

For further understanding of the use of the bio-ecological model in research and its application to this investigation, it is useful to interrogate how others have employed the framework, including scrutiny of the disciplinary fields in which it has been used, the purposes for which it has been employed, and the extent to which elements of the model have informed advancements in knowledge and understanding.

2.5.1 General application in research

An overview of literature suggests that the model has enjoyed a healthy degree of popularity in scholarly work. Subscription to Bronfenbrenner's ideas is evident in many areas of social science, linked predominantly to research about children. In particular it is evident in research conducted in the fields of social work (such as Schweiger and O'Brian, 2005; Lee *et al*, 2010), education (for example, Fumoto *et al*, 2004; Tissington, 2008), and child health and rehabilitation (for instance, Schonkoff *et al*, 1992; Sontag, 1996; Stolzer, 2005; Algood *et al*, 2011). An ecological orientation can also be traced in studies not linked to children (for instance, Thurston and Vissandjée, 2006; Kulik, 2007) and also in research outside social sciences (such as Beaton *et al*, 2008).

The model is predominantly evident in literature published in the USA, but also to a certain degree in wider international studies, where researchers have investigated

global phenomena within national contexts. For instance, Lee *et al.* (2010) used Bronfenbrenner's concepts to conduct investigation in South Korea, Thurston and Vissandjée (2006) in Canada, Kulik (2007) in Israel and Tyson (2011) in the UK.

A shared feature of such studies in terms of interpretation and application of Bronfenbrenner's model is their overriding focus on one or more elements of the bio-ecological framework, rather than subscription to the whole integrated system of ideas. For instance, Schweiger and O'Brien (2005) addressed the role of social environments and their processes in relation to adoption of children with special educational needs, but paid no regard to person-related characteristics. Similarly, Lee *et al.*'s (2010) evaluative study of empirical investigations into suicide amongst young people specifically addressed micro to macrosystems, but did not examine person characteristics or interactions within such environments. Stolzer's (2005) reconceptualization of perspectives on Attention Deficit Hyperactivity Disorder (ADHD) was also concerned with multiple influences, in particular reciprocal processes between, for instance, mother and child, but did not take account of person-related elements and the characteristics of ADHD which might influence such interactions.

Others have focused more on 'person' and personal attributes. For example, Algood *et al.*'s (2011) research about maltreatment of children with developmental disabilities emphasized the socio-demographic characteristics of those involved. Tissington (2008) scrutinized the attitudes of trainee teachers in various social contexts involving peers, mentors and instructors in a range of school sites – how these trainees interacted with such social environments was, however, omitted in the research. Similarly, Kulik's (2007) survey research with 275 volunteers examined the personal attitudes they brought to their volunteering activities and interrogated how variables in the micro to macrosystems correlated with their characteristics and experiences.

While this quantitative study linked person and context, it again disregarded the qualities of the interactions involved.

Wider scrutiny of Bronfenbrenner-inspired work, however, provides examples of more all-round utilization of the model. An important example is Odom *et al.* (2004), which analysed current understanding of classroom inclusion involving children with special educational needs and disabilities, as evident in research published in the USA between 1990 and 2002. The conceptual analysis was framed by using all four elements of the bio-ecological model. In relation to person, the authors noted how children's impairments and the impact of these on learning were examined in the reviewed publications. In relation to context the researchers sought connections between children's impairments on the one hand and forms of inclusion on the other, while stakeholders' values and attitudes were investigated within micro- to macro-environments. Scrutiny of process encompassed instructional approaches, curriculum strategies and social interactions between disabled and other children. Finally, Odom *et al.* used the 'time' element to interrogate how various social systems changed to accommodate disabled children's needs. Even so, the researchers did not review interactive, reciprocal interactions and pedagogical strategies reflecting the nature of inclusive educational practice.

Other researchers have been particularly interested in how Bronfenbrenner's system of ideas might be reconceptualized for use in empirical studies. For instance, Tudge *et al.*'s (2009) systematic review of 25 research studies, all published between 2001 and 2008 in the USA and claiming use of the bio-ecological model, scrutinized challenges associated with empirical application of the whole model. This review found that only four of the papers examined applied three or more elements of Bronfenbrenner's later theoretical framework – Campbell *et al.* (2002), Riggins-Carpers *et al.* (2003), Tudge *et al.* (2003) and Adamson *et al.* (2007). The remaining studies were described thus:

Some authors treated the theory as though it was a theory about the various systems of context and their influences on development, thereby missing the ecological nature of the theory even its earliest form... as though Bronfenbrenner was simply a theorist interested in contextual influences on development (Tudge *et al*, 2009, p206).

2.5.2 Disability-related research

As has become apparent, one area of social science which has been particularly interested in employing Bronfenbrenner's model is that of disability-related studies. Traditionally research in this field has examined the experience of disability either as a deficit exclusively related to the individual, or as a social disadvantage derived from hostility of society (a dichotomy examined in more detail later in this study). More recently, however research is emerging that addresses these two factors as interactive, rather than deterministic, phenomena. Interconnections between characteristics of the physical, social and attitudinal environments on the quality of participation in activities and indeed on overall quality of life were examined in the first stage of the EU-funded, longitudinal, quasi-experimental 'Sparcle Project' (Colver, 2010). This involved 818 children, aged 8-12 years and all diagnosed with cerebral palsy, and their parents from nine regions of seven European countries (Denmark, England, France, Germany, Ireland, Italy, Northern Ireland and Sweden). Findings of this multi-staged and multi-method study included the idea that considerable variations in policy and practice affected the well-being of these children. For instance, national legislative frameworks, education and social-care policies, together with support mechanisms at local and individual levels, had differing outcomes for families participating in the research and influenced in particular the means by which children had access to public and support services and how parents themselves were supported in their parenting roles (Colver, 2010).

In this light, Bronfenbrenner's model therefore offers a sophisticated way of examining intricate connections between child-related and environmental influences, establishing not simply a bridge, but an interface between the two.

Sontag (1996), in particular, was drawn to the bio-ecological model, calling it 'an intuitively appealing paradigm' (p322) for special-education research. For her, its benefit lay in its potential to bring together perspectives from a range of individuals and practices involved with the child, as well as the interactions between these agencies. More specifically, according to Sontag, the model helped to see child-related characteristics – including the impairment or disability itself – more as 'stimulus characteristics' that 'invite or discourage particular kinds of reactions from the environment that can either disrupt or foster the development of the child' (p325) than simply as deficiency. Indeed, Bronfenbrenner's own perspective was that these child-related characteristics, including those linked to disability, defined 'self' as a dynamic agent which actively contributed to interaction with the environment (Bronfenbrenner, 1992).

2.5.3 Problems of application

As was apparent earlier in this chapter, Bronfenbrenner's principal concern was to develop detailed and explicit phenomenological understanding of the complex conditions of children's development. He wished also to use this understanding to influence social processes, such as parenting, childcare and education. His constantly advancing model reflected these aspirations, strengthened by his strong concern for children's real-life experiences. Many subsequent studies have sought to use the model with similar ambitions.

Bronfenbrenner (1979) wanted understanding of the complex conditions for child development, as evident in his model, to influence social processes such as parenting, childcare and education. Nevertheless, his theoretical ideas seem to have attracted more interest amongst scholars than amongst those with professional, policy or practice-related interests. Thomas (1996), who critiqued the bio-ecological model as part of analytical evaluation of a range of developmental theories influential in the USA, described it as having potential to produce 'widespread and fruitful research' (p389), but maintained that this potential was yet to be realized. Scrutiny of the literature suggests that this is still largely the case.

As has been seen, the model became increasingly intricate over time, incorporating multi-faceted connective features. Its changing nature arguably made the model too challenging for use within individual investigations, and – crucially – too complex to create impact and inform practice within empirical settings. Significantly too perhaps, Bronfenbrenner never conducted his own empirical investigations to illustrate application of his ideas, therefore providing no examples to follow. Instead, he scrutinized and reflected on previously conducted studies to elucidate his points. This high level of abstraction remains problematic in Bronfenbrenner's writing and provides another reason why the model has done relatively little to inform actual policy development and advancement of professional practice.

Nevertheless, Bronfenbrenner's basic assumptions, articulated in a wide range of propositions and arguments, can be seen as clear, comprehensive, convincing and showing internal consistency (Thomas, 1996). His writings as a whole are systematic, understandable and logical, possible reasons why they have informed so much scholarly work. These positive features may be helped by the fact that Bronfenbrenner's ideas were neither wholly novel, nor revolutionary. What he accomplished, as discussed earlier, was to extend and integrate already formulated

concepts and theories, in particular from Lewin and Vygotsky, and to turn these into a retuned, integrated system of thinking, encompassing and reflecting the complexity of child development itself and the ways in which this development might be investigated.

2.5.4 Application to this study

This study has directly drawn on Bronfenbrenner's most mature form of bio-ecological perspective, depicted in the 'person-process-context-time' (PPCT) model, to examine outlooks on the early development and learning of young children with cerebral palsy. The attractiveness of the model as a framework for this study reflected the match between the wide-ranging nature of the investigation's topic and the all-encompassing, phenomenological nature of the framework itself. Its use enabled the research to seek a more comprehensive and sophisticated understanding of the experience of disability, through the lenses of a range of stakeholders and of children themselves, than that derived from approaches framed solely around singularly medical or social perspectives.

A second benefit of the model was its heuristic nature (Sontag, 1996), which facilitated an increasingly complex, exploratory strategy designed to answer the research questions. The model could guide the study's progression from literature review to its empirical sections through an orderly, rational system of ideas (Maxwell, 2005). It also guided the empirical investigation itself, aiding the identification, analysis and critical comparison of values, procedures, practices and outlooks, located in a range of social and professional environments, and helping the investigation to seek increasing detail in a logical fashion.

Challenges of using Bronfenbrenner's model needed, however, to be addressed. The first of these was its changing nature, in particular from its 'ecological' to 'bio-ecological' characteristics. As already indicated, this study took on Bronfenbrenner's later, fuller, bio-ecological stance, taking into account all four elements of the model: person, process, context and time. The reason for this related to the wish to provide a wide-ranging analysis of the chosen topic and to reflect the intricate nature of relevant factors and influences contributing to it. In this respect it seemed right to make use of Bronfenbrenner's more complete perspective, rather than to limit the study by applying only parts of this conceptualization.

Another danger was the model's 'abstraction'. The stance taken in this study in this respect is that the choice of whether to produce 'abstract' outcomes or those of a more empirically useful nature depends to a large extent on the researcher and on his or her decisions about what to produce from the data collected. The aim of this investigation was not ultimately to provide a map, chart or conceptual theory of factors relevant to provision for children with cerebral palsy and their families. Rather it was to affirm a specific identity for these children and to examine perspectives from a range of sources which might illuminate manifestation of that identity for those involved in that field. While not 'abstract' therefore, the study was not wholly 'practical' – it sought a position between these two characteristics, one whereby understanding of a neglected group could be increased and whereby more developed understanding of their position might inform both thinking and, perhaps, practice in this field.

The most challenging aspect of Bronfennbrenner's model for the researcher is, however, its complexity. While it is feasible and justifiable to agree with Thomas (1996), who considered the multiple elements and dimensions of the model to be more a dynamic feature than a drawback, the model's sheer intricacy nevertheless

needs to be addressed in some way and the chosen approach articulated clearly, if Tudge *et al.*'s (2009) warning of potential 'conceptual incoherence' (p199) is to be avoided.

The first task for the researcher, therefore, is to gain a structured understanding of what is going on in the investigation. An important feature of this study in this respect is its focus on 'outlooks' – the perspectives not only of parents and professionals of various kinds, but also those of children, as evidenced in their responses to practical activity in relevant settings. It was from these outlooks, rather than from other more formalized or quantifiable sources, that the study's outcomes were produced. A second task is to clarify the extent to which Bronfenbrenner's model is used to determine the nature of the research. In this study, the four elements of the model provided a structure for investigation – however, this did not mean that all possible aspects of each element were addressed. Instead the study defined which aspects were to be scrutinized, thereby delineating the range of data to be collected and the analytical framework by which 'outlook-based' results were to be produced.

In most respects, therefore, Bronfenbrenner's PPCT model acted as a structure for the study's research questions – four out of the five questions directly represented the model's elements. The fifth overlapped all four of these categorized elements, and allowed the study to examine the whole, multi-faceted picture from the perspective of children's observed, real-life experiences. Figure 2.1 shows this correspondence of research questions with the four PPCT elements (not quite, it will be noticed, in this order), further informed by this connective 'perspective' relating to children themselves.

Person	Context	Process	Time
RQ1: How is the identity of young children with cerebral palsy in relation to their development and learning perceived by their parents, early-years practitioners and representatives of local-authority support services?	RQ2: How are the contexts in which support for their development and learning is provided viewed by these stakeholders?	RQ3: What are these stakeholders' perceptions of the processes by which development and learning of these children takes place?	RQ4: In relation to time, how are future priorities and possibilities for development and learning of these children viewed by these stakeholders?
RQ5: How is this range of outlooks evident in observed practical interactions between children and practitioners?			

Table 2.1: Mapping of research questions in relation to elements of the bio-ecological model

Taken as a whole, therefore, this framework prioritized the children themselves in the overall picture produced, a reflection perhaps of the study's aim to produce and promote a developmental and educational 'identity' for this group. Indeed, it was here where most complexity was found. The focus of the study was young children within the local authority who had been identified as having cerebral palsy. However, it was important to remember that these were not simply individuals with a disability, but human beings with multiple identities (Gilroy, 1997; Coster, 2007). They were young, growing persons whose upbringing and early education were influenced by social, cultural and pedagogical values. They were participants in early-years provisions and recipients of additional services. They were sons or daughters and sometimes siblings within their immediate family; they had friends and were part of the local community of other families and children. Their lives were located within a particular historical and economic time, where local and central policy defined their development and learning needs and the means by which these were met.

2.6 Conclusion

The bio-ecological model is a complex and comprehensive projection of Bronfenbrenner's understanding of child development. Despite its complexity and

abstraction it provided for this study a logical and systematic framework for the examination of multiple dimensions of the research issue and the connections between them. It informed the study as a whole and design of the research questions and analysis of data in particular. It also provided a basis for examination of literature which informs the focus of the study – this review now follows.

CHAPTER 3: REVIEW OF THE LITERATURE

3.1 Introduction

As established, Bronfenbrenner's framework provides an overall research strategy for this study. This literature review has also been developed with the model's multi-elements in mind.

3.2 Person

The first task is to develop an understanding of the various ways in which perceptions of disabled children, in particular of those who have cerebral palsy, are formulated in the literature. Exploring the development of images of the 'person' and 'person-related characteristics' are central to bio-ecologically driven investigation (Odom *et al*, 2004; Smart, 2009).

3.2.1 Models of disability

The literature is by no means short of paradigms by which representation and personal experience of disability can be projected. These relate mainly to different 'models' of disability (Oliver, 1990, 1996; Goodley, 2001; Shakespeare, 2006), seen to permeate thinking on policy and support systems, social, legal and professional arrangements and the way in which related research is designed and conducted (Bickerman *et al*, 1999; Smart, 2009). The models can also contribute to the ways in which a person's self-identity is formed and to the perceptions of significant others –

parents, professionals, policy-makers – about the disabled person and about their roles in relation to this person (Landsman, 2005; Fisher and Goodley, 2007).

Medical or social?

Conventionally, there are two predominant, contrasting models of this kind: medical and social. The medical model of disability is the more orthodox perspective. It is seen to emphasize pathology and dysfunction (Smart, 2009; Llewellyn and Hogan, 2000); it gives rise to categorization of disability, 'labeling', and in the view of critics to segregation and oppression of disabled people (Oliver, 1996; Swain and French, 2000). Under this model, responsibility for adapting to the challenges of everyday life is largely assigned to disabled people themselves (Llewellyn and Hogan, 2000), with little regard to societal influences, and application of the model reflects the idea of the disabled person's 'normalization' (Reindal, 2008; Smart, 2009). Research investigations adopting this model may seek correlation between the nature of the impairment and the extent to which it causes personal disadvantage. In spite of its deficit orientation, the medical model has enjoyed prestige and credibility, especially in scientific and health-related fields, and has also been a traditional bedrock for special education (Thomas and Loxley, 2007; Reindal, 2008; Farrell, 2010), including its processes of identification and early intervention.

In contrast, the social model constructs meaning by observing and understanding societal circumstances. The model rejects the idea that disability arises from individual deficiency, often – as pointed out by Shakespeare (2006) and Llewellyn and Hogan (2000) – articulated as 'tragedies'. Instead, causal responsibility is assigned to society, whereby inadequate policies, mechanisms and processes oppress and disable individuals and prevent them from fulfilling their potentials and aspirations (Oliver, 1996; Goodley, 2001). Empirical investigations based on this model are habitually

emancipatory in methodology (Barnes, 2003; Burke *et al*, 2003), using phenomenological approaches to draw attention to perceived oppression stemming from societal values and processes (Reindal, 2008).

'Blurring' of boundaries

The contrast between medical and social models therefore explains differences in values, perceptions and practice, both in research and in professional activity itself. Recently, however, there has been increasing concern over limitations in both models in projecting real-life experience (Shakespeare, 2006). In particular, their shortcomings in informing childhood disability research have been increasingly scrutinized (Llewellyn and Hogan, 2000; Lindsay, 2003; Connors and Stalker, 2007).

One illustration is highlighted in Landsman's (2005) ethnographic study in the USA with mothers of infants and young children diagnosed as having, or being at risk of developing, disabilities. The researcher, herself a mother of a young child with cerebral palsy, was engaged with 60 families of such children. Through participant observation of intervention sessions, as well as interviews with about a third of these mothers and with involved professionals, the study explored the nature of mothers' understanding of disability and influences on their constructs of their children's identities.

These mothers clearly encountered and complied with the medical model after their child was born. Medical assessments and identification of their child's developmental delay were powerful influences. Hearing the label, receiving news of disability in a way which suggested doctors had 'written off' their child (Landsman, 2005, p125), and the repetitive experience of seeing and hearing confirmation of their child's deviation from

normal development and the need for specialist input – all reinforced medical and deficit-oriented perceptions of their child.

However, this did not result in mothers' unconditional acceptance of such viewpoints. Often, intuitively, they rejected the first diagnosis or prognosis. Some claimed to be experts in their own child and fought against the disabled label, in some cases finding themselves then being labeled as 'not facing reality' (Landsman, 2005, p129). Their narratives showed shifts from one model to another, a blurring of boundaries between them, and even negotiation between the models over time. In this way Landsman's (2005) observations reveal a much more complex situation, with the two models shifting and interacting in real-life perspectives.

Reindal (2008) suggested that the choice between over-medicalizing or over-socializing disability ignored the overlap which reflects actual experience. While understanding the models' helpfulness in informing policy, professional practice and research, Llewellyn and Hogan (2010) viewed both as deterministic and uni-directional, representing the stance of their advocates rather than the experience of disabled people themselves. Similarly, Smart (2009) felt the dichotomy was morally biased, providing culturally and historically time-bound representations of certain dimensions of disability.

What has been called for instead is a more situational, interactive perspective, combining both outlooks. Shakespeare (2006) in particular has highlighted the urgent need for a more balanced and coherent rationale, of greater relevance for caregivers, practitioners, researchers and disabled people. For others too (Llewellyn and Hogan, 2000; Reindal, 2008; Smart, 2000), reconceptualization involves a synergic outlook, rediscovering the relational aspect lost with the dichotomy approach (Reindal, 2008).

3.2.2 Vygotsky: a socio-cultural outlook

A more informative outlook on disability is found in Vygotsky's psycho-pedagogical concepts. These ideas have been less applied in western academic and professional communities than the Russian psychologist's conceptualization of child development in general (Gindis, 2003). However, his practice-based observations and theoretical interpretations may invigorate current, rather stagnated policy outlooks for young disabled children, including those with cerebral palsy, and – as Gindis (1995) indicated twenty years ago and Bottcher and Dammeyer (2012) more recently – have the potential to move forward understanding and practice of upbringing, early childcare and education.

Influences on development

The uniqueness of Vygotsky's views on disability is first of all derived from his ontological outlook on the nature and impact of organic physical, sensory or intellectual impairment. Vygotsky's (1993) conceptualization of its origin, manifestation and implications is not linear, uni-dimensional or reductionist, exclusively linked to deficiencies either of the individual or of society, but resonates with more interactive perspectives, with emphasis on multiple, complex and overlapping influences determining the course and nature of a disabled child's development. Vygotsky (1993) represented disability as a situated, socially and culturally determined, interactive phenomenon.

Two of Vygotsky's notions are particularly relevant for interrogating development and learning attributes of children with cerebral palsy. The first derived from his generic conceptualization of child development as a culturally and socially determined process (Ageyev, 2003; Kozulin, 2003), what Gindis (1995, p156) called a 'socio-cultural

developmental phenomenon', not altogether different from general child development. What he observed and discovered as part of 'paedology' (study of the child), however, was linked and applied in 'defectology' (study of the defect), as translated and explained by Gindis (1995). Accordingly, the way in which a disabled child's developmental qualities and characteristics are perceived and projected is subject to socially and culturally determined outlooks. Interpretations of the child's strengths and difficulties are directly linked to the social and cultural environments that are pertinent in the child's life and are influenced by the norms, expectations and demands embedded in these contexts. In Vygotsky's (1993) epistemology, study and understanding of the attributes and characteristics of a disabled child can therefore only emerge if the particular features of relevant social and cultural environments are properly understood. This notion signals the contextual, rather than universal, nature of child development, in particular when a barrier to development is present.

The second of Vygotsky's ideas relates to the multi-faceted nature of child development. In Sutton's (1980) interpretation this outlook had two aspects: quantifiable biological processes, such as generic growth and sensory maturation, and neurological changes, linked to and enhanced by individual experience. Observations of both processes can lead to generalized observations about child development.

Even more decisive than these is another process, linked to alterations in the child's disposition and character. Such changes, as highlighted also by Sutton (1980), can only be mapped and comprehended as a series of qualitative alterations in a child's personal characteristics. For Vygotsky (1993) such modifications stemmed from social and cultural influences, again making the process highly contextual. Subsequently, when disabled children's development is interrogated, in the view of Vygotsky (1993) the focus should be on social, emotional and cognitive qualitative implications, rather than on the transformations that derive from quantifiable biological and neurological

maturation. Examination of these changes might involve scrutiny of the ways in which the child perceives, adapts and responds to the series of social scenarios or of situations where an absence of such responses is evident.

Nature of disability

In this way Vygotsky (1993) rationalized the nature of disability, seeing its consequences in two dimensions. The first of these involved 'primary implications' (Vygotsky, 1993), manifested in a child's limited capacity to perform lower-level functions such as moving about, using hands, speaking, hearing or seeing. The second and more developmentally pivotal dimension emerged from the impact of these primary implications on higher levels of psychological function such as motivation, interest, planning or problem solving. Vygotsky perceived these latter cognitive processes as pre-requisites for the child to establish connection with his or her physical and social environment and therefore as core conditions for socialization. Analogously, in relation to a disabled child's development, it was not the 'primary', predominantly organic difficulty which hindered participation in everyday activities, but the 'secondary' implications, manifested in limited higher levels of psychological and cognitive function. Such secondary implications therefore became the main reason for an altered course of development. This notion challenged previous perspectives which attempted to understand an impairment's developmental consequences through examination of specific organic deficiencies. Vygotsky did not deny the existence of the biological or neurological difficulties associated with various conditions, but was more concerned with understanding their implications for a 'cultural line of development' (Bottcher and Dammeyer, 2012, p434). As stated in Vygotsky (1993, no page): 'A child whose development is impeded by a defect is not simply a child less developed than his peers but a child who has developed differently.'

Social implications

Importantly, this notion lessens the significance of remedial strategies focused simply on compensating disabled children for their organic weaknesses or limitations. Indeed, Vygotsky rejected special provisions which predominantly addressed the primary implications in movement, vision, hearing or understanding (Gindis, 2005). Instead he emphasized the need to address social implications, because, as he explained: 'Whatever the anticipated outcomes, *always and in all circumstances* development, complicated by a defect, represents a creative (physical and psychological) process' (Vygotsky, 1993, no page, italics in original). In other words, the process of development for disabled children involved establishing new, qualitatively different opportunity for the child's social interactions.

According to Vygotsky, potential for such qualitatively different routes came from 'within-child compensation', based on adaptable capacities of the human neuro-psychological system. His illustrative example came from Stern (1921, in Vygotsky, 1993) and concerned a visually impaired child who would use psychological and cognitive functions, such as determination, estimation and planning, to orientate within the physical environment. Within-child compensation overrides organic deficiency and becomes the source for developmentally instigative experience (Gindis, 2005), with the child performing at a higher developmental level by activating psychological functions and skills associated with more advanced stages of development. Outcomes are achieved '*another way, by another course, by other means*' (Vygotsky, 1993, no page, italics in original). In this way Vygotsky conceptualized impairment not as a weakness, but as a spur to growth and to mastery of skills.

The merit of this conceptualization for this study lies in its focus on exceptionality not as a deficiency, but as a stimulus for purposeful practice in parenting and upbringing.

It also moves discussion towards the notion of 'process', to be scrutinized in relation to broader and more pragmatic perspectives later in this review.

3.2.3 Cerebral palsy

Before then, and aside from theoretical debates, it is necessary to consider cerebral palsy in a more straightforward manner as one of the most common forms of physical disability amongst young children (Parkes *et al*, 2001). This involves scrutiny of the various ways in which the condition has been defined or conceptualized, problems associated with its identification and measurement of prevalence, and differing perceptions of its implications for learning and development.

The term itself was originally used in Osler's book, 'The Cerebral Palsies', published in 1889 (Kavčič and Vodušek, 2005), although William Little's earlier scientific descriptions meant the condition's more historical label was 'Little's disease' (Bleck, 1975). While Little attempted to depict the range of difficulties associated with the condition, Osler's work was the first to indicate its neurological origin and complex nature. Osler recognized that cerebral palsy was not a disease or malfunction of the body, but a condition caused by damage to the developing brain, resulting mainly in co-ordination difficulties. Furthermore, by use of the term 'cerebral palsies', he implied its varied and multi-faceted origin and characteristics. This discovery was then elaborated by Freud in 1893, who suggested a system of classification for motor difficulties with a neurological origin, known by then by the overarching term, 'cerebral palsy' (Bax and Brown, 2004; Kavčič and Vodušek, 2005).

Designation and terminology

Medical research continued to search for more clarity in designation. Kavčič and

Vodušek's (2005) systematic review of scientific definitions of cerebral palsy published between 1916 and 1992, included the following in its findings: a congenital and non-progressive condition; manifested in reduced muscle control impacting on voluntary movement; an overarching category, including many different kinds of disorders and symptoms. Armstrong (2007, p166) summarized the condition as a 'group of disorders' with various manifestations and degrees of impact on an individual's development.

In the social sciences an additional focus has been on the perceived usefulness of terminology. Some authors have preferred to indicate the condition's general physical nature, using the term 'motor deficit' (Cogher *et al*, 1992), 'motor dysfunction' or 'motor disorder' (Levitt, 2010), 'motor impairment' or, most generally of all, 'physical disability' (Fox, 2003). Alternatively the condition's impact on development may be stressed, encapsulated in terms such as 'developmental disability' (Gersh, 1998), 'developmental co-ordination disorder' (Baxter and Rosenbloom, 2005) and – reflecting Vygotsky's outlook – a 'disorder of development' (Sutton, 2008).

Sutton (2008), the author who coined the 'disorder of development' term, did not simply critique the social adequacy of the label, 'cerebral palsy', but also its attendant descriptions. From a psycho-pedagogical point of view, he argued that such medically driven elucidations 'are not sufficient in themselves for effective understanding of the lives of children and adults and their families affected by cerebral palsy, and what might be done to enhance this'. In Sutton's reasoning – which bears close resemblance to Vygotsky's distinction between primary and secondary implications of developmental disability discussed earlier – the chains of social and psychological consequences are more pertinent than biological or neurological origins. Medicalized perspectives therefore limit the emergence of new constructs which would contribute

to better appreciation of social processes related to upbringing of children with this impairment.

Garner (2009) nevertheless raised doubts about the usefulness and adequacy of these alternative descriptors for parents and practitioners in educational settings. Parkes *et al.* (2001) too argued in favour of the original 'cerebral palsy' term, suggesting that it had 'some meaning and usefulness in a wider social context, for example for families, people with cerebral palsy, service providers and the generic public' (p15).

'Cerebral palsy' remains indeed the most commonly used term. It is widely accepted in parental, educational and other professional conversations, in scientific and social investigations, within disabled people's own associations, and in the public domain, for example in media coverage of the personal lives of current political figures (Summers and Sparrow, 2009; Davey, 2011). Nevertheless, according to Corbett (1996, p34), social or disciplinary 'ownerships' – medical or therapeutic, sociological, psychological or educational – continue to influence the way in which the condition itself is assigned within overarching categories such as 'special educational needs', 'disability' or 'physical impairment'. This results in a rather intricate overall discourse which is 'often vague, malleable and used interchangeably' (Oliver and Barnes, 1998, p14).

Identification and prevalence

Such lack of clarity causes difficulty when identifying and determining prevalence of the condition. In response to equality legislation in the Disability Discrimination Act (1995), local authorities maintain case registers about disabled children and young people. However, in an email to this researcher dated 6 September 2010, the 'Response Service' of the national charity for people with cerebral palsy, Scope,

suggested in bold font that '**extreme caution has to be applied to any data on cerebral palsy**', due to the lack of trustworthy national statistics. The use of diverse terminology is likely to be one reason for this difficulty – Mooney *et al.* (2008) also identify inconsistencies in recording, categorization, data collection and reporting.

Parkes *et al.* (2001) found that the most reliable information was provided by a collective register maintained by five health authorities between 1960 and 1984, known as the 'United Kingdom Collaboration of Cerebral Palsy Registers'. This reported between 60 and 100 new cases of children with the condition each year. Nevertheless, the authors had doubts about the extent to which the figures covered all such births, and whether all those recorded did in fact relate to cerebral palsy. In their recommendations they suggested that for service planning and delivery, maintaining incidence statistics (the number of cases within a defined population) would be more appropriate than relying on prevalence data (the number of children born and diagnosed per year).

International statistics share similar tensions. Johnson's (2002) comparative study on prevalence of cerebral palsy in six European Union countries (Italy, Denmark, UK, Sweden, Ireland, France) suggested between 1.49% and 2.63% per 1000 live births. Other studies have reported statistically significant differences between national registers, although these seem to relate more to unreliability and inconsistency of procedures for diagnosis, than to risk factors and trends in frequency of the condition (Cans, 2000; Johnson, 2002; Miller, 2007).

There is some agreement that in spite of medical advancement the overall rate is not falling, but has leveled out (McCarthy, 1992; Stanley *et al.*, 2000). Bax and Brown (2004) point out that while improvements in obstetric care have reduced more traditional causes, such as trauma at birth, they have at the same time increased the

survival rate of preterm babies. This is likely to increase incidence (Meadow and Newell, 2002) and the degree and complexity of difficulties which children with cerebral palsy may experience (Parkes *et al*, 2001).

Development and learning

Literature related to these children's development and learning draws on cumulative understanding in different ways. Most reflects medical and health-related perspectives of the disability, focusing on problems of motor co-ordination, gross and fine movement, balance and mobility, combined with cognitive, speech, sensory or perceptual difficulties (Cogher *et al*, 1992; Fox, 2003; Hinchcliffe, 2007; Farrell, 2008). These commentaries invariably advocate therapeutic, rehabilitative routes to enhancement of development, involving physiotherapy, speech and language therapy and occupational therapy, alongside fairly non-specialized educational approaches, albeit often within special educational settings. Allied to this is use of personalized equipment such as standing and walking frames, communication aids, adapted shoes, braces and splints.

Some have argued that such therapeutically-based techniques and aids encourage only the child's passive participation and called instead for more pedagogically oriented, problem-solving challenges to stimulate more active utilization of physical and higher-level psychological and cognitive functions. Hári and Ákos (1988) and Hári (1997a), for instance, echoing Vygotsky, suggested that cerebral palsy is only destructive when its associated motor co-ordination problems hinder the child from executing voluntary actions derived from his or her internal interests and intentions. In these circumstances development becomes 'dysfunctiós' – 'dysfunctional' (Hári and Ákos, 1971, p122). However, such dysfunction is amenable to change – appropriate pedagogical guidance and support can reverse the process. In this case the child

regains the temporarily lost interest and inner drive and actively responds to the challenge of a given situation. Hári and Ákos (1971, p122) describe this process as the child's development becoming 'orthofunctiós' – 'orthofunctional'. Therefore – again resonating with Vygotsky – it is not the degree, extent or complexity of an organic difficulty which is responsible for the child's altered development, but the associated psychological and emotional functions which underpin a child's behaviour – interest, confidence and motivation to succeed. If social situations are created which stimulate and address these, then development can take place.

Sutton (2008) elaborates on Hári and Ákos' (1988) explanation when considering cerebral palsy as a 'disorder of development'. He suggests that the child's challenges of motor co-ordination, such as moving about, using hands, sitting, standing and walking, should not be the main concern for parents and educators. More significant are the emotional, social and intellectual difficulties which the child encounters as the result of unsuccessful attempts at physical or other accomplishment in social contexts and the processes by which these difficulties may be overcome. Debate of this kind again takes scrutiny into the area of 'process', to be examined more closely later in this review.

Child, family and society

The effects of cerebral palsy are undeniably present in children's lives from the onset of development, shaping in individual ways their daily, age- and context-related experiences. These effects are also embedded in the personal or professional experiences of a range of stakeholders involved in a child's early nurturing. Management of physical, sensory and often health-related difficulties associated with the condition become part of everyday reality for all concerned (Read, 2000; Shakespeare, 2006). This 'additionality', as Norwich (2002) describes it, demands

particular responses from the child and significant others, from the community and wider society. The last words in this section, describing this situation in personal terms and moving discussion on to the contextual issues examined in the next section, go to a 'blogger', David (2008):

I have spastic and athetoid quadriplegic cerebral palsy (CP). Over the years, I have met many other people with CP, and one thing is for sure – cerebral palsy is different in each one of us. I have high tone and spasms in my legs and arms, and low tone in my trunk and neck, and athetosis in my arms and hands.

With CP, life is full of complicated decisions. I've learned that every decision has a positive and negative. Every choice has a positive consequence and a negative consequence. Sometimes the consequences are short term, sometimes they are long term. And, often, when making a choice, you just don't know what the consequences will turn out to be. As I now weigh decisions on my class schedule, exercises, rest, and fun activities that challenge me physically, I understand more how difficult it was for my parents to make decisions for me when I was younger.

3.3 Context

Perspectives on disability and cerebral palsy lead to consideration of the second and perhaps most complex aspect of Bronfenbrenner's bio-ecological model: 'context'. This involves examining changing policy and conditions for these children's early development and learning.

3.3.1 Responsibility

Official Government and local policy in this area, informed by international trends, has involved a long and mainly gradual transfer of professional responsibility from medical

and specialist environments to more educational and community-based services. Over time there has also been considerable growth in general provision for pre-school children, expanding the array of professionals and practitioners involved. Under the Education Act (1944), schooling for children with disabilities was based on age, ability and aptitude (Garner, 2009), with the assumption that the child – if ‘educable’ – should fit into an established educational setting. If they had complex difficulties – this would include many children with cerebral palsy – they could be regarded as ‘ineducable’ (Fox, 2003) and their care maintained within the family or assigned to health-related provision.

The Education (Handicapped Children) Act (1970) replaced the notion of ‘unsuitable for education at school’ with that of the educability of all children. Children with more complex needs could no longer be bypassed, resulting in substantial growth in segregated special education – Fox (2003) reported an increase in the number of special schools in the UK between 1945 and 1955 from 528 to 743, rising by 1977, according to Booth (1981), to 1,653.

Despite such new educational obligations, provision remained based on traditional, deficit views of disability, with strong and separated dualism of mainstream and special educational services. Hegarty (1993, p43) critically reviewed this system:

Pejorative and isolating; it gives a misleading basis for planning appropriate educational provision, frequently, indeed, distorting the pattern of provision; and above all it implies and reinforces a mistaken understanding of the nature and causes of learning difficulties.

3.3.2 Mainstream or special?

The seminal Warnock (1978) report and the subsequent Education Act (1981) confirmed the ideal of 'education for all'. The Act replaced categories of handicap with umbrella concepts of 'special educational needs' and 'learning difficulties'. It also established the principle of educating these children, whenever possible, as part of mainstream rather than segregated provision, and introduced the formal process of a 'Statement of Special Educational Needs', which stipulated responsibilities in relation to those with complex needs. Compliance with the Act also meant that parents had to be consulted and involved in their child's assessment and in decisions on allocation of educational provision. Ratification of international agreements, for instance those relating to the rights and welfare of children (United Nations, 1989), followed by the national endorsement of the Salamanca Statement (United Nations Educational, Scientific and Cultural Organisation, 1994), also influenced the evolving outlook.

The Education Act (1993) led to the introduction of the 'Code of Practice for the Identification and Assessment of Special Educational Needs' (Department for Education, 1994), which confirmed the priority given to local, community-based, mainstream provisions for children with disabilities. Procedures, rights and responsibilities, to which all local authorities and schools were required to 'have regard', were revised seven years later (Department for Education and Skills, 2001), promoting the idea that the education of such children could no longer be a minority concern: 'All teachers are teachers of children with special educational needs' (p44). A 'graduated response' was outlined, including at various stages design of individual education plans (IEPs), a strong role for the Special Educational Needs Co-ordinator (SENCo) in schools and early-years settings, involvement of external agencies, and a voice in key decisions for parents and for children themselves. Legal reinforcement for this policy outlook came with implementation of the Special Educational Needs and

Disability Act (2001), SENDA, which outlawed discrimination against those with special needs and disabilities.

Tensions

By the new millennium the SEN agenda had established clear momentum in education policy. Nevertheless, the system could be seen as increasingly idiosyncratic – not because of its underlying inclusive values, but, as Booth (1996) asserted, due to the utopian outlooks upon which implementation was envisaged. One of these entailed unresolved conflict with other values which also increasingly underpinned the educational system, mainly those relating to the raising of standards of achievement (Tomlinson, 2005; Thrupp and Tomlinson, 2005). Such tensions created specific dilemmas: the extent to which learners' specific characteristics should be identified, the relevance of a common curriculum for disabled learners, and the choice of educating all children together or in separated provision. Norwich (2008) conceived these quandaries as 'dilemmas of difference' (p449), 'whether to recognize or not to recognize differences, as either option has some negative implications or risks associated with stigma, devaluation, rejection or denial of opportunities' (p448).

Others drew attention to the need to balance the human-rights element of educational inclusion with pedagogical considerations (Lindsay, 2003; Wedell, 2008; Lewis and Norwich, 2005). As Wedell (2008, p130) explained, 'pedagogy is relevant because it represents the interaction between the learner and the teacher... Policies should specify the optimal circumstances in which successful learning and teaching can take place'. Sutton (1999), examining trends in provision for children with cerebral palsy, similarly warned of the limitations of purely contextual outlooks:

Including children with cerebral palsies means more than installing ramps and special toilets. If school is going to meet all a child's complex learning

needs, education has to mean more than simply access to the National Curriculum (p22).

Both the original and the revised Code of Practice allocated an important role in special educational needs provision to early-childhood services. 'Excellence for All Children' (Department for Education and Employment, 1997) set out practical guidance for early identification and multi-agency co-ordination. Other developments strengthened these approaches: roll-out of baseline assessment (School Curriculum and Assessment Authority, 1997); implementation of the first Curriculum Guidance for the Foundation Stage for 3-5 year olds (Qualifications and Curriculum Authority and Department for Education and Employment, 2000); and implementation of an assessment profile (Department for Education and Skills and Qualifications and Curriculum Authority, 2003).

Such changes altered the role of special nurseries and special schools. After decades of strong, segregated identity, the number of special schools actually fell, Lipsett (2007) reporting a decline in the number of Statements of Special Educational Needs and closure of 150 special schools between 1997 and 2007. Those special schools which remained became increasingly seen, at least in part, as a base for specialist services in the wider community, including very early family support for children with disabilities. Moreover, the change took place just as early-years provision for all children itself began to develop in a substantial way.

3.3.3 Growth of early-years provision

Origins: care or education?

Early outlooks on pre-school education were reflected in a report from House of Commons Education, Science and Arts Committee (1989): 'The aims for under fives

are basically the same as those for any other phase, with the exception that very young children need a considerable additional amount of care. Care and education for the under fives are complementary and inseparable.’ The Rumbold report (Department for Education, 1990) referred also to this traditional duality when examining characteristics of the early-years context, noting how nurseries, crèches and playgroups, largely in the private and voluntary sector, were more associated with the former, while nursery classes and nursery schools provided educational provision within the maintained sector. Coherent early-years provision, said Rumbold, could only be developed if there was greater integration of the two.

Indeed, this dichotomy caused variations in the quality of provision and its availability. Bertman and Pascal (2002) and Wolfendale and Robinson (2006) pointed to its patchwork nature and the short-term nature of national priorities and local arrangements. Pugh (2014) describes how provision at that time was heavily reliant on the private and voluntary sector, offered diversity but little parental choice and encompassed a variety of aims and a lack of service co-ordination.

Special educational needs

This ‘patchwork’ situation inevitably influenced how early-years services responded to children with special educational needs and disabilities. While the Rumbold report recommended consultation with parents, it was still the 1981 Education Act which applied: priority of early-years placement to be given if the child had an identified special need, but with limited indication about what such placement should include.

Wolfendale (1997) noted greater access to a range of individual, early-intervention ‘outreach’ provisions; Carpenter (1994, p10) urged ‘dynamic early intervention services that can enable families in an active dialogue with professionals meeting the

needs of children'. However, generic, mainstream, early-years provision itself did not include specific concern for special educational needs. An example of this was one of the earliest curricular policies, the 'Desirable Outcomes for Children's Learning on Entering Compulsory Education' (Department for Education and Employment and School Curriculum and Assessment Authority, 1996), which included brief mention of pre-school children with special educational needs, but no discussion of their learning requirements.

Significant and rapid developments came with the 1997 New Labour government's commitment to improve educational services and reduce social exclusion, reflecting the 'determination of a strongly interventionist central government to impose its agenda' (Blakemore and Griggs, 2007, p145), but described by Leach (2011, p21) as an 'exciting period for people involved in the early years'. Issues relating to special educational needs began to be considered within the broader priority of improving social inclusion (Norwich, 2000; Tomlinson, 2005). The 'Every Child Matters' agenda, leading to the Children Act (2004), set out the Government's aspiration for provision to meet diversity of need. Services – education, health and social care – were amalgamated to strengthen integrated work. Early-years co-ordination was sought first through SureStart centres, then through children centres, with their number increasing rapidly over the years (Roffey and Parry, 2014), not only as part of social welfare improvement, but also as a way of drawing women into economic activity and the labour market (Levitas, 2005). The 'Common Core of Skills and Knowledge for the Children's Workforce' (Department for Education and Skills, 2005) was introduced, reflecting requirements for higher-quality services across the sector.

Policy developments overall sought to pull resources together. 'Aiming High for Disabled Children: Better Support for Families' (Department for Education and Skills, 2007a) stipulated provision to families of a key worker to co-ordinate agency

involvement and promoted Family Service plans to secure parental participation in planning and assessment of children's progress. In Roffey and Parry's (2014) view, this New Labour initiative was consistent with previous policy directions on identification and early provision within a multi-agency context. Aubrey (2014), however, highlights the potential challenges for practitioners working in altered contexts of this kind: the need to adapt current practice, address new issues and set aside status, professional hierarchies and agency culture – all of which were likely to affect progress with the Government's agenda at that time.

Parental involvement

Another element strongly promoted as essential to effective provision has been that of parental involvement, with children's needs increasingly seen as part of the needs of families as a whole (Carpenter, 2007). Nutbrown and Clough (2006) described this concept, which they trace back to the 1930s, as both a shared value and a shared set of practices, a way of thinking and of action.

The Rumbold report (Department for Education, 1990) called parents the most important educators of young children. Legislation from the Education Acts (1981) and (1993) gave parents the right to appeal against professional decisions. Statutory guidance placed on professionals the duty to liaise with, inform and listen to parents, while the SEN Code of Practice (Department for Education and Skills, 2001) emphasized parents' vital contribution to understanding of their children's needs. New Labour's ten-year childcare strategy (Department for Education and Skills, 2004a) promoted greater choice for parents in the placement of their children.

The picture has not all been positive, however. Read (2000) found that parental involvement often caused them stress and could be more a difficulty than a help.

They were frequently dissatisfied about unmet needs of their child and had to deal with discrepancies in professional opinions, a lack of co-ordination between services and a power imbalance in relationships, with professionals taking a stronger role: 'When [professionals] are face to face with the mother of a disabled child, the playing field can hardly be said to be level' (p64). Nevertheless, while noting 'the complexity of the situations ... and the taxing nature of the problems that they face' (pp67-68), Read (2000) admired the 'active strategies [parents] develop to manage and resolve a range of problems and dilemmas' (p68). Laing (2011) pointed out the source of some of those problems: 'Those with children under five and their families appear to be at the mercy of any ill-informed and ill-advised early years policy the governments choose to throw at them' (p68).

Curriculum

Parallel to advancement in provision, the educational content of services progressed also. 'Curriculum Guidance for the Foundation Stage' (Qualifications and Curriculum Authority and Department for Education and Employment, 2000), for practitioners working with children aged three to five, was implemented, followed by 'Birth to Three Matters' (Department for Education and Skills, 2002), for those working with babies and toddlers. Principles in both documents informed the subsequent 'Early Years Foundation Stage Framework (EYFS)' (Department for Children, Schools and Families, 2008a) and its revision four years later (Department for Education, 2012a).

Central to the implementation of the EYFS was a national, statutory commitment to increase the quality of early provision. EYFS became the basis for a developmentally appropriate, play-based curriculum for young children (Langston, 2014; Pugh, 2014), claiming to respect developmental and cultural diversity, create a bridge between families and settings, eliminate the gap between care and education and provide a

pedagogical tool for practitioners to assess and further children's development (Palaologou and Male, 2013).

The EYFS set standards and requirements regardless of children's backgrounds and abilities (Langston, 2014) and established expectations for practitioners to collaborate with parents and other professionals to enhance children's progression (Palaologou and Male, 2013). However, Leach (2011) warned that while intentions were laudable, some implications were not. For instance, concern in the EYFS for cognitive and some aspects of social development was seen by Leach (2011) as disproportionate, with its goal orientation confusing notions of play, learning, nurturing and teaching.

Voluntary organizations

Amid the growth in infrastructure, it is easy to overlook the contributions made by voluntary organizations to provision for children with special educational needs and disabilities. Miller (2000) points out how historically these children and their families were the concern of many such bodies, either through direct services such as play schemes, holiday support and short breaks, or specifically to parents through support groups, information services and legal advice. The voluntary role has often been acknowledged as part of a partnership strategy, for instance in the Every Child Matters agenda (Department for Education and Skills, 2004b) and 'Excellence for All Children' (Department for Education and Employment, 1997).

More recently, policy has proposed an increased role for voluntary organizations in collaborative working (Department for Education, 2010; Department for Education, 2011). However, remits of voluntary organizations may contradict with priorities of national policy (Low, 1998; Miller, 2000), in particular when these organizations provide advice and advocacy to families that put pressure on statutory bodies to

improve provision. Parents may view them in a more positive light than some of their statutory counterparts (Williams, 2011, in Ekins, 2012). In these circumstances it is reasonable to envisage that sustaining an increased role in educational policy, at the same time as responding to families' demands, will require difficult repositioning and compromise in the practice of such organizations.

Conductive education

One type of largely voluntary-based provision, of particular relevance to children with cerebral palsy and their families (and included amongst venues for data collection in this study), is conductive education. Despite the growth of inclusive thinking and practice, it continues to follow a traditional specialist model of provision, locationally separate from other services.

Conductive education is a pedagogical system, developed in Hungary since the 1940s and internationalized since the 1970s (Sutton, 1986; Hári and Ákos, 1988; Garner, 2009). In the UK it largely became known through a BBC television documentary called 'Standing Up for Joe', which recounted a British family's visit to the Pető Institute in Budapest seeking appropriate provision for their small son, who had cerebral palsy (BBC, 1986). The film showed a stark contrast between well-meaning but unstructured provision in England and more assured and pedagogically sophisticated provision in Hungary. The Hungarian system seemed to have expectations for movement, mobility and independence which were absent from English statutory support (Somerset How, 2010). Sutton (2010, pxiii) has regarded the conductive-education approach as a 'whole new life style' and a unique form of upbringing with expectations for development of every aspect of children's lives.

Perhaps unsurprisingly the approach attracted controversy as its popularity in the late 1980s grew. Oliver (1989), as a disability activist, famously called it 'theoretically unproven, practically unsubstantiated and ideologically unsound' (p198). A parental response from Beardshaw (1989) showed the other side of the argument:

[Oliver] and other writers have dissected the inadequacy of current approaches to disability... and called for higher standards... They have analysed the way that children with disabilities are encouraged to be passive recipients of care... They have emphasized the need for higher expectations from society as a whole what disabled people can achieve. Conductive education is about high expectations... [it] is about motivating people to achieve things for themselves, and, in doing get more control over their lives (p297).

The lack of an established discourse about the approach has remained a source of concern, however. The difficulty is not the amount of research completed over the years. Indeed, a range of studies has been undertaken, most notably comparative research commissioned by the Department for Education (Bairstow *et al*, 1986) and investigations by Petersen (2000) and Stiller *et al*. (2003), none of which found substantial benefits in the conductive-education approach. The source of argument has been more over the focus and nature of these investigations, and in particular their quasi-scientific rationale and methodologies which separate the child from his or her wider social context (Llewellyn *et al*. 1997).

Similar concerns have recently been reiterated at a more evaluative level by the Centre for Research and Dissemination (2014), also known as Cochrane Reviews. The reviewers' meta-evaluation of two systematic literature reviews which suggested that conductive education was not effective in enhancing development and functionality of children with cerebral palsy (Ludwig *et al*, 2000, and Darrah *et al*, 2003) concluded that studies on conductive education were poorly described in their objectives and vaguely defined in their outcome measures. They lacked consideration

of environmental factors and of perspectives of children and their parents, and failed to provide explicit definition and explanation of the parameters of conductive education.

Other studies have sought to examine conductive education as a social, rather than scientific phenomenon, for example Lind (2000) and Baker (2009). Overall, Sutton (2014) calls research 'one of CE's big problems' and a call by Lambert (2004) for more extensive discourse on conductive education's professional and pedagogical methodology is yet to realized.

Nevertheless, the approach has become a desirable alternative to other kinds of early-years provision. This is in part, it seems, due to its high expectations towards development even when a child had complex difficulties (Westcott, 2010). The website, Conductive Education Information (2014), reports 41 places offering some kind of provision in the UK. These are largely associated with voluntary organizations and private services, but are in some cases part of statutory provision, as reported in studies by Coles and Zsargo (1998), Wilson (20010, Lambert (2004) and Baker *et al.* (2010).

3.3.4 Current developments

Since 2010 the coalition government has continued to support an integrated approach in the early years, despite austerity measures leading to closures and amalgamations of provision. As Pugh (2014) points out, according to the Organisation for Economic Co-operation and Development (OECD) the UK has become high spenders internationally on pre-school provision, with free nursery education accessed by 93% of three-year-old children and 98% of four-year-olds.

Within the mixture of provision, the main focus is now on stimulating local markets of private, voluntary and other independent providers. Drawing on independent reports from Field (2010) on poverty in early childhood, Allen (2011) about early intervention and Tickell (2011) about the Early Years Curriculum Framework, a national, evidence-based strategy for supporting young disabled children and their families has emerged. This is focused on improving children's readiness for formal schooling, strengthening parental rights and engagement, improving the quality of services through better-equipped practitioners and strengthening partnership amongst stakeholders.

A range of initiatives has been introduced in relation to these priorities. New Labour's top-down focus on inclusion has been put to the side in response to difficult economic times (Teather, 2012), while the system for special educational needs itself is to be tackled by 'radical reform' (Department for Education, 2010; 2011). There have been plans for improvements to administration, parental choice, practitioner training and collaboration between education, health and social care (Department for Education, 2011); a streamlined single assessment process with more child and family involvement; an integrated 'Education Healthcare' (EHC) plan to bring services together; and personal budgets for families linked to their EHC plan. Implementation of all such initiatives, including long-awaited revision to the Code of Practice, was finally undertaken in September 2014.

Parallel to the special needs system, the context for supporting young children's early learning has also undergone significant alteration. A revised EYFS framework (Department for Education, 2012b) is more focused than its earlier version on the role of parents, as well as on children's all-round development, with simplified early learning goals and assessment procedures. The new framework continues to emphasize the need for a well-equipped workforce and the responsibilities of local authorities and the inspection agency, Ofsted, to produce clear guidance to settings

on the quality of their provision. Although changes have been generally welcomed, Palaiologou and Male (2013) have highlighted continuing scepticism about the appropriateness of a centrally prescribed, standardized and closely monitored programme for very young children. Langston (2014) has similarly asserted:

Learning can be sometimes difficult to make sense of since learning pathways are not always linear, nor are learning trajectories immediately measurable. The art is in making young children's learning visible and, as advocates of children, helping policy makers to understand its value (p187).

3.4 Process

Langston's (2014) observation leads to scrutiny of 'process', namely what is done socially and pedagogically to nurture development of young children with cerebral palsy.

3.4.1 Family relationships

There is a plethora of research which investigates the association between young children and closest family members, usually the mother, as the earliest social platform for development and learning. Themes covered in such research include the 'attachment' between child and main caregiver, the nature of dyadic and other interactions between them and the role of wider-family members in the child's developmental processes.

‘Attachment’

Studies on ‘attachment’ invariably draw on the ideas developed by John Bowlby, a British psychologist, and Mary Ainsworth, one of his students. Origins and development of their work, spanning fifty years in the last century, are described in Bretherton (1992). Citing other commentaries, the basic theory is presented thus:

Although human infants initially direct proximity-promoting signals fairly indiscriminately to all caregivers, these behaviors become increasingly focused on those primary figures who are responsive to the infant's crying and who engage the infant in social interaction (Schaffer & Emerson, 1964). Once attached, locomotor infants are able to use the attachment figure as a secure base for exploration of the environment and as a safe haven to which to return for reassurance (Ainsworth, 1967; Schaffer & Emerson, 1964). How effectively the attachment figure can serve in these roles depends on the quality of social interaction, especially the attachment figure's sensitivity to the infant's signals, although child factors also play a role (Bretherton, 1992, p766).

For children with a developmental disadvantage or congenital disability, this sense of attachment is frequently seen as being at risk. One strand takes a view that attachment may be inappropriately or inadequately formed because of the child's early difficulties (Howe, 2006; Marlow, 2007; Carpenter, 2007) – disability hinders the baby from responding to stimuli, thus adversely affecting growth of a close relationship with the main caregiver. Prolonged hospitalization at the start of life may also be an obstacle (Carpenter, 2007) – the ‘hi-tech’ medical environment may separate baby from caregiver and create delay or dysfunction in this respect (Chesney and Champion, 2008). Others, for example Gopnik *et al*, (1999) and Parker-Rees (2007), suggest that every baby has a neuropsychological capacity to relate to positive stimuli and that a more important area for scrutiny is the mother's reaction to this capacity. Focusing on babies with congenital difficulty, Hadadian (1995) and Woolfe *et al*. (2002) examined caregivers' attitudes towards disability, their ‘grieving’ for what may

have been lost in terms of normal upbringing of their child and the adjustments they had to make in relation to the child's needs.

Identification of such factors can be made using the 'Infant CARE-Index' (Crittenden, 2005), which assesses mother-infant interactions in the child's first two years according to the mother's sensitivity, control and unresponsiveness and the child's cooperativeness, compulsivity, difficultness, and passivity. Information gained provides a basis for planning intervention to improve parent-child interaction, including in situations where the child has physical and learning disabilities.

A third set of perspectives finds more positive features in the mother-disabled child relationship. For instance, Pianta's *et al.* (1999) study concluded that the intensified practical and hands-on tasks required when caring for a disabled child increased mothers' sensitivity and responsiveness, resulting in stronger attachment. Howe (2006) and Guralnick (2011) argue that in such situations there is a combination of influences, derived from both the child and the mother, and that this combination needs to be considered when examining early attachment processes.

Dyadic interactions

Some commentators have been concerned more specifically with the nature of social exchanges between the disabled infant and the main caregiver. For instance, in relation to infants with cerebral palsy, Howe (1995) examined how parent-initiated interactions can awaken the baby's interest, stimulate physical and sensory development, encourage early formation of 'self' and lay foundations for later communication and social exchanges.

Finnie (1974) and Ákos and Ákos (1991) were also interested in this dyadic interface in relation to children with cerebral palsy. They argued that if regular and sustained, and with participation on both sides, interactions need not be dysfunctional, but can be a positive source of development. The mother could become increasingly knowledgeable and confident, not simply understanding the baby's difficulties and needs, but also her or his likes, dislikes and capabilities. According to Ákos and Ákos (1991), this understanding could then be used regularly, repetitively and purposefully by the main caregiver to create enjoyable play activities. In this case, the child would continue to show interest and respond positively to the caregiver's invitation to engage and, as a result, would develop elements of movement and co-ordination previously thought to be difficult or beyond their capability. Finnie (1974) similarly explained how such pleasurable play activities could help the child to move from dependency towards greater independence. Finnie argued that motivation was imperative, awakening and intensifying the use of senses, communication, visual tracking, turning, touching and feeling, and helping the baby to develop from passivity towards alertness and receptiveness to stimuli from the social and physical environment.

Highlighted by both Finnie (1974) and by Ákos and Ákos (1991) is the goal-oriented nature of desirable dyadic interaction. The infant does not simply like the shared 'games', but also shows a desire to engage and be involved. This then helps to sustain the mother's attention, in turn triggering more physical, emotional or vocal responses from the child, including those which would in other circumstances appear too difficult to achieve. If over time such interactions are enjoyable and productive, both the infant and adult reach their goal: the infant gains the mother's attention, while the mother becomes increasingly reassured that her child is capable not only of responding, but of learning too. Conditions for attachment are met reciprocally and enhance the child's early development.

These views resonate closely with Vygotsky's perspectives about the role of adults in children's learning. Without the parent, the young disabled child would show behaviour corresponding only to his or her current level of development. The young child with cerebral palsy, therefore, would be likely to remain passive in use of senses, movement and communication. However, with persistent and sustained interaction, the mother or other main caregiver can help the child to progress within Vygotsky's (1987) famous 'zone of proximal development', this being 'the difference between the child's actual level of development and level of performance that he achieves in collaboration with an adult' (p209). If attachment is secure, the baby feels reassured, while the caregiver becomes confident in adjusting expectations and input, thus refining and extending the zone within which interactions take place. To characterize the thoughtful, pedagogically oriented nature of this co-operative process, Hári asserted that 'love is not enough here. It must be intelligent love' (1988, in Sutton, 2010, pxii).

Wider family

So far discussion has focused on dyadic interactions as a mother-infant endeavour. In contemporary discourse, however, it is well established that a father's involvement also helps to shape a child's early development and learning (Biller, 1993; Lamb and Tamis-LeMonda, 2004; O'Brian, 2005). Scholarly work on this theme is nevertheless rather insubstantial, perhaps because of what Beresford (1995) highlighted as fathers' qualitatively and quantitatively different function within the family. In Read's (2000) research, mothers perceived themselves as having a central role in their child's upbringing, while their male partners were more involved with practical jobs, family leisure activities and random parenting tasks demanded by particular circumstances. Similarly, Pelchat and Lefebvre (2004) found that mothers attuned their roles to the

day-to-day care of their disabled child, while fathers tended to relate their own responsibilities to their child's activity in the wider, outside world.

Relatively little is known also about disabled children's interactions with siblings. Research has been more concerned with the relationship between non-disabled siblings and parents and with the psychological implications of growing up in a family where a brother or sister is disabled (Williams, 1997; Guite *et al*, 2004). Similarly, grandparents' relationships with their disabled grandchildren are a largely uncharted area. Scherman *et al*. (1995), Hastings (1997) and Lee and Gardner (2010) are exceptions – they identified complications in the grandparent-disabled child relationship, often due to grandparents' difficulty adjusting emotionally to their grandchild's disability. As a result, grandparents contributed to household chores and occasional childcare, rather than getting involved more closely with bringing up the disabled child (Lee and Gardner, 2010).

3.4.2 Professional interventions

Early professional intervention invariably recognizes the strong influence of family-based experiences for very young disabled children (Bronfenbrenner, 1974; Heinicke *et al*, 1988; Guralnick, 1991). Intervention may focus on remediation of family difficulties (Porter, 2002) or seek to address the child's atypical development and its social consequences. It may also have long-term aims, hoping to prevent further difficulties in later life (Nutbrown and Clough, 2006). Four types of early intervention employed for children with cerebral palsy are examined here: Portage work, therapies, inclusive or segregated statutory educational provision, and the less orthodox approach of conductive education.

Portage work

Based on an American model, Portage work began in the UK in the 1970s (Russell, 2007). It has now become one of the most widely available family-based support systems for young children with cerebral palsy and their families in this country (Hayward, 2006). The approach supports families with young children with additional needs in their own homes (Cameron 1997); it is seen as educational and family-centred and based on a premise that children can be helped through largely triadic interactive activities with parent and a professional (Claire and Pinstrang, 1995; Nunkoosing and Phillips, 1999). Russell (2007) has regarded it as a way of empowering parents and engaging them in their child's development

The Portage-work process has a number of distinct stages. It begins with a home-based assessment during which the practitioner, with the parent, establishes targets for the child's development. Subsequent home visits provide opportunities to model to the parent how to use child-initiated and adult-selected play activities to work towards these targets and how to monitor progress on a regular basis. The Portage worker also encourages the parent to share queries and observations, to discuss issues related to the child's advancement and to consider involvement of other possible services (Hayward, 2006; National Portage Association, 2014).

Pain's (1999) study with parents of young children with physical disabilities examined their perceptions of how Portage work contributed to parenting. Three main areas of benefit were identified. The first was the support Portage offered with management of their child's difficulties, such as feeding, sleeping and management of behaviour. The second was the increased understanding it provided about their child's development. The third was how Portage workers helped with interpretation of medically based reports and other professional information. However, Pain's survey also illuminated

parents' frustration when their Portage worker did not know enough about other available services or when a suggested service was not available in their area.

Russell (2007) regarded the Portage model as capable of meeting the complex demands of disabled children and their families on a widespread basis. This was recognized at national-policy level when the approach informed professional priorities in 'Together from the Start' (Department of Health/Department for Education and Skills, 2003). Indeed, Russell's (2011) audit in the UK, the sixth of its kind, reported increased demand for the service over the last decade, with a steady growth of Portage workers between 2005 and 2009. However, a decline in numbers from 2009 was considered by Russell (2011) to be the result of a changing economic climate, with emerging alterations in the composition and background of Portage personnel, reductions in the frequency of home visits and switches from these to setting-based group-play sessions.

Therapies

In its information bank about early intervention (Scope, 2014), Scope, the largest voluntary organization for people with cerebral palsy and their families, recommends twelve professional services for families with young children with this condition. Ten of these are therapeutic or medical in nature (the others being Portage work and conductive education). Although increasingly seen as deficit-orientated (Fisher and Goodley, 2007; Roffey and Parry, 2014), physiotherapy, speech and language therapy and occupational therapy, as well as medical interventions such as Botox and muscle-relaxing drugs, remain the most common forms of professional support for these children.

Studies of therapies, for instance Caro and Derevensky (1991) and Østensjø *et al.* (2003), often focus on their role in strengthening functionality in areas such as mobility, hand co-ordination, communication and feeding, achieved through sessional intervention. Passive exercising, positioning and use of specialist equipment during everyday activities are regarded as appropriate for maintaining or rehabilitating children's development (Stanton, 2002; Hinchcliffe, 2007). While much early therapy is provided in small-scale interactions in the child's home, much is later provided within developmental centres or at school. The processes associated with these larger contexts, in particular their influences on educational provision itself, are examined below.

Statutory provisions

Indeed, sooner or later early professional intervention extends beyond intermittent, home-based input and becomes a more complicated, multi-professional and multi-contextual endeavour (Roffey and Parry, 2014). Dyadic or triadic interactions are replaced by relationships within more extended nursery or school contexts, involving other children and several adults. While it is anticipated that children with cerebral palsy should attend mainstream settings (Department for Education and Skills, 2001), for some – due to their complex difficulties and medical needs – more specialist educational provision is seen as more appropriate (Westwood, 2013). For a few, a combination of mainstream and special settings may even be needed (Department for Education and Skills, 2007a). In all situations – mainstream, special or combined – new considerations and processes arise. For children with cerebral palsy these relate mainly to curricular principles and practice and to the use of the therapeutic services, resources and advice described above.

Irrespective of the setting the young disabled child attends, the curricular basis for learning and development is provided by the previously mentioned 'Early Years Foundation Stage (EYFS)' for children from birth to five, originally presented as Department for Education and Skills (2007b), and subsequently updated by Department for Children, Families and Schools (2008a) and Department for Education (2012b). Langston (2014) reminds us that the EYFS is not a syllabus, but a framework – it does not give guidance for practitioners about what activities to plan, deliver or observe, but instead provides underpinning principles, standards, steps and anticipated outcomes designed to steer early-years practice towards more effective developmental and educational provision.

The four underpinning principles established in the original EYFS of 2008 were presented as: 'Unique Child'; 'Positive Relationships'; 'Enabling Environments' and 'Learning and Development'. These resonated with recommendations offered by earlier government-commissioned, large-scale, longitudinal evaluative studies, such as Moyles *et al.* (2002), Siraj-Blatchford *et al.* (2002) and Sylva *et al.* (2004). Amongst a range of recommendations, these studies highlighted correlation between the quality of social interactions and positive outcomes in children's social and cognitive development.

The need to meet diverse needs of children is stressed under all of the four themes, as expressed in the earlier version:

Meeting the individual needs of all children lies at the heart of the EYFS. Practitioners should deliver personalised learning, development and care to help children to get the best possible start in life... [The practitioner] should take into account the differing needs of individual children within the setting and tailor... [the] approach to each child's needs (Department for Education and Skills, 2007b, p6).

In line with its overall orientation the EYFS recommendations for work with children with disabilities focus on policy and procedures, such as closer partnership with parents and professional cooperation. The appointment of a key worker is seen as an important element in this process, designed to 'ensure that every child's learning and care is tailored to meet their individual needs' (p7) by engaging with parents and synchronizing support from specialist services. The main pedagogical platform in this curricular framework is 'play', although Leach (2011) and Haughton and Ellis (2013) have highlighted limitations in how this is advocated. Leach, for instance, is sceptical about the link with particular learning outcomes, suggesting that play cannot underpin the curriculum, as 'children play because that is what children do' (p27).

For young children with disabilities, especially cerebral palsy, the EYFS is often accompanied by therapeutic and medical input (Roffey and Parry, 2014). Moreover, educationalists themselves are likely to draw on these processes when considering their own input. Fox (2003), Willis (2009), Farrell (2011), Westwood (2013) and others address processes for positioning and handling of the child, facilitating communication and adapting the environment to promote social and physical access for educational purposes.

Use of equipment and personalized devices, such as mobility and communication aids, equipment for posture, positioning, feeding and toileting, is a particular area in which educational discourse draws from therapeutic expertise. Some authors, such as Finnie (1974), Willis (2009) and Westwood (2013), identify this as one of the most important strategies for facilitating children's access to the physical environment and social interactions.

Others, however, have taken a different view. For instance, the study by Hemmingsson *et al.* (2009) found that teachers in schools were often unsure about

how to use such equipment. Huang *et al.*'s (2009) research provided similar, but more specific conclusions, highlighting that children tended to reject use of such devices in social and educational environments because they preferred to receive help from others or to do things in their own way. Parents also often dismissed such equipment, sometimes because it was not practical for their home environment, sometimes because its use produced adverse social responses and interfered with the child's natural activities. Both studies suggest that if strategies are transferred from one professional context to another without rationalization, the child's participation in activities may be lessened, rather than facilitated.

Although affected by tensions, the dominant ideology in all curricular processes has been one of inclusion – a philosophy, according to Sutton (2000, p32), of 'High Moral Grounds' (author's capitals), whereby values take precedence over actual practice. Sutton's own view is more pragmatic:

All children should be not just educated but educated *well*, in ways that are educationally appropriate and offer families a reasonable degree of choice, to match their children's education to their goals and values; this in full recognition that children change over the course of childhood, with any upbringing and education worth their salt playing a prime role in this (Sutton, 2000, p32).

Sutton goes on to stress the absence of a shared pedagogical outlook, responsive to demands of contemporary society, which might inform upbringing and education of disabled children, also the lack of agreement about the nature and processes of such pedagogy and about the responsibilities it would entail for different stakeholders. Without considering such pedagogical dimensions, Sutton believes, inclusion remains utopist and alienated from the needs of disabled children, their families and practitioners. He advocates revitalization of the special-education discourse, which in his view has become non-existent as a result of an almost obsessive national commitment to developing inclusive educational systems.

In similar if less forthright ways, Lindsay (2003) and Wedell (2008) argue for closer consideration of disabled children's needs, rather than legislative considerations, with a healthier balance sought between contextual issues and learner characteristics. In relation to very young children, Sylva *et al.* (2004) has also stressed the need for development of pedagogy, incorporating 'interaction traditionally associated with the term "teaching", the provision of instructive learning environments and "sustained shared thinking" to extend children's learning' (p1). Norwich and Lewis (2005) are even more pragmatic. They pose the dilemma whether contemporary pedagogy for learners with disabilities and learning difficulties should reflect a generic pedagogy for all children or be specific to particular groups. They examine this question in relation to an extensive range of impairments, analyzing the specialist pedagogical approaches available to each, but sadly omitting those relevant to children having motor difficulties such as cerebral palsy.

Conductive education

One specialist system which Norwich and Lewis and (2005) could very appropriately have considered is conductive education. As described earlier, the approach was developed for children with motor disorders and despite not becoming an established element of British early intervention and education, it has been an unorthodox option for families with young children with such difficulties during its thirty-year history in this country.

There are many interpretations of the pedagogical principles of conductive education in the western discourse, many of them personal accounts by participants or professionals. As Sutton (1986) indicated, because its practice is hard to describe, observers may be selective in what they capture. Hári (1997b) offered several values to explain its practice, including the notion of 'orthofunction' referred to earlier; the role

of the children's group and of its specialist educators, the conductors; and the system's integrated learning programmes. These pedagogical tenets have been examined in a range of other, more independent commentaries also.

The first, 'orthofunction', reflects the system's objective to develop socialization so the individual with a disability can become an active and capable member of society in relation to age and context-specific demands of everyday life (Hári and Ákos, 1988). Sutton (1986) similarly explained the concept as both social and developmental: the individual through learning develops higher levels of personal attributes, which, together with appropriate assistance from the social and physical environment, create conditions for intentional participation in activities. Orthofunction is therefore related both to the individual and the environment – the individual learns to respond to the environment, which changes accordingly to accommodate the individual's needs.

A second principle is that interactive group work, as described by Baker and Sutton (2006), is seen as the optimum circumstance for the early learning of most children. While the benefits of learning in groups is not a unique discovery, the conductive-education system can be seen as innovative in its use of group work to activate children's interest, motivation, activity and independence (Hári and Ákos, 1988), aspects more difficult to stimulate in dyadic or triadic interactions. In the case of infants, conductive education also involves parents in the group, who therefore gain confidence and skills to interact with their child, both within and outside formal sessions (Jernquist, 1986; Baker, 2009).

Such collective group work is successful if individual experiences are 'orchestrated', contributing to learning by being heterogeneous in terms of children's level of development, interests and previous experience, but homogeneous in relation to common tasks provided by the conductor (Hári and Ákos, 1988; Horváth, 2006).

Conductors, trained to deliver conductive-education programmes as described by Brown and Mikula-Toth (1997), use their understanding of children's personal and environmental obstacles to learning, together with their observation of practice, to design curricular activities at individual and group levels, co-ordinating both the work of the group and the contribution of each child and being ready to recognize when goals and expectations and circumstances for learning need to be advanced (Hári, 1997a).

Importantly, conductive education does not categorize children's areas of development or allocate specific areas to different specialist professionals. Instead, programmes are designed to encompass a range of opportunities for developing movement and co-ordination, communication and self help through age-appropriate play or school activities (Hári *et al*, 1991). As Rozsahegyi (2006) described, promoting such all-round development is only possible if the conductor organizing and guiding the child's activities is aware of the learning opportunities contained in various activities. Integration of these into a unified daily routine gives opportunity for learning, reinforcement and application (Hári *et al*, 1991; Hári, 1997a); the child is viewed from a holistic point of view and is seen to learn and develop as a whole (Wilson, 2001).

3.5 Time

The final part of this review addresses the last conceived and perhaps most abstract bio-ecological element, that of 'time'. Bronfenbrenner defined this as 'change or consistency over time, not only within the person but also of the environment in which the person lives' (1994, p40).

In this study, time is addressed as a way of understanding outlooks on children's progression through the early-years system and their future beyond it – 'subjective predictions about the future' (Russell, 2003, p145). Such expectations usually reach beyond the notion of legislative rights, hidden or overt, and are in most cases constructed in order to achieve or at least to negotiate better life chances and outcomes for disabled children (Read, 2000). Expectations examined in this review are those of parents – those of a broader range of stakeholders, including practitioners, have not been usefully addressed in the literature. This absence leaves a gap in understanding how future aspirations for children influence educational practice and additional support.

3.5.1 Influences on parental expectations

Evidence from Brotherson and Goldstein (1992), Wolman *et al.* (2001) and Flewitt and Nind (2007) suggests that the child's disability is a dominant element in parents' forward-looking thinking. Others – Read (2000), Fisher and Goodley (2007) – have found parents expressing more socially oriented wishes for a future free from social oppression. Legislation giving stronger rights to parents is a likely influence on either outlook, potentially helping them to think confidently about the future and establish their own roles within professional procedures. However, Brett (2002) has pointed out how expectations are individual and highly contextual. Russell (2003) stressed that parents often modify every aspect of their lives to meet their child's needs, adjusting emotionally, establishing new social encounters and assimilating information relating to their child's condition. They develop their ideas about their child's short and long-term future on the basis of these individual experiences.

Landsman (2005) and Fisher and Goodley (2007) have examined other factors affecting parental outlooks, including parents' own upbringing and education, their

perceptions about disability, and their daily, hands-on experiences with their child. Also influential are the systems by which their child's needs are assessed and identified, including professionals' attitude to the child's disability and how diagnosis and future prospects are communicated.

3.5.2 Parental aspirations

In their aspirations for children's overall development, parents have been seen by Wolman *et al.* (2001) to have strong concern for psycho-social well-being. For instance, they wish for their child to be healthy and happy, to have strong self-esteem and to enjoy successful relationships and opportunities in everyday life. A wish to increase children's independence in mobility, communication and self-care is also evident in accounts by parents themselves, such as McDowell (2010) and Kelly (2010).

Wolman *et al.*'s (2001) investigation, which interviewed parents of 63 children with chronic conditions, including eight with cerebral palsy, confirmed such outlooks. However, although generally positive about their children's current situation, the parents were less optimistic about the future. They expressed concerns about the difficult life likely to lie ahead for their child, the potential for lowered self-esteem, expected problems with independent living and communication, and even deterioration in capabilities over time.

Similar concerns were highlighted in Wolman *et al.*'s investigation with respect of education, although parents' worries were more towards contexts and processes than towards children's progression. Brotherson and Goldstein's (1992) study highlighted parents' wishes for support services to be part of the child's educational routine, also a desire to get on well with support practitioners. Russell (2003) asserted that parents of

disabled children expected good communication with settings and wanted reassurance that practitioners were fulfilling their roles in meeting their child's needs.

Such parental doubts about the maintenance of specialist input in new settings are a common theme in relevant literature. Children's well-being is seen as strongly dependent on service support, but deficiencies are perceived in integration of educational provision and specialist input, accompanied by pressure on parents themselves to complete 'tasks' with their own children, with little professional understanding of family routines and obligations (Brotherson and Goldstein, 1991). Russell's (2003) later study found similar apprehensions, clustered around parents' understandings of professional practices and the wish to have good interactions with practitioners.

3.5.3 Transitions

One final, important element of aspirational thinking, examined by Brandon (2000), Mulvihill *et al.* (2002), Knoche *et al.* (2006) and others, relates to the child's progression from one developmental or educational setting to another. Welchons and McIntyre (2014) argue that the challenges associated with such transition, experienced by any child, parent and even practitioner, are intensified when the child is disabled, the issue of choosing suitable provision being more problematic than for other children.

Flewitt and Nind's (2007) multi-method study interrogated parents' rationales for choosing pre-school settings for their disabled child. Parents living in rural areas found pre-school choices inadequate, while those elsewhere found them limited by local-authority attitudes, procedures and shortages in funding. Advice from professionals was often conflicting, making it difficult to come to a decision. Finally, parents' own

perception of disability, as well as their perceptions of practitioners' understanding, was influential in the process of choosing their child's educational provision.

Flewitt and Nind (2007) also examined parents' perceptions of different types of services. Inclusive pre-school settings were seen as locally available, convenient provisions that strengthened children's social development and identities in the community and facilitated subsequent routes to mainstream education. However, parents were concerned about high child-to-adult ratios and weak staff expertise in such settings. In contrast, specialist provisions were regarded as better equipped to provide more individualized and intense input, which in the views of many was imperative for their child's learning. The experience and expertise of practitioners in these settings were also attractive, and some parents saw increased opportunities for their child to socialize with others with similar difficulties. However, these services were often perceived as being unavailable in their neighbourhood, or to be non-inclusive.

In Flewitt and Nind's (2007) research, parents often avoided choosing between the two options by preferring a combination of both – 'the best of both worlds' (p440). Russell (2011) similarly highlighted how parents could delay selection of a particular setting, citing a range of reasons: lack of confidence in practitioners' experience, doubts about maintenance of specialist input, or a lack of appropriate provision.

Professional difficulties may intensify the challenges of this process (Welchons and McIntyre, 2014). Clough and Nutbrown's (2004) national, multi-method study of practitioners working with young children with special needs found that lack of personal experience, relevant training and understanding made it hard for many to support families when choices about the child's future needed to be made. Rozsahegyi (2008) interrogated 198 evaluation forms from 285 practitioners attending

short and extended professional development courses on work with young children with cerebral palsy between 2004 and 2006. Respondents had broader backgrounds than expected – they included early-years practitioners, education psychologists, local-authority personnel, child minders, Portage and social workers, therapists, researchers and a doctoral student. The whole range of attendees expressed a desire to strengthen their understanding of cerebral palsy and similar motor difficulties. They wanted practical guidance about strategies, resources and equipment, rather than theoretical training. Similar wishes for practical advice about children with cerebral palsy have been highlighted in Buell *et al.* (1999), Rose and Coles (2001) and – from the view of parents – in Perrin (2008).

3.5.4 Opportunities and challenges in society

Overall, the discourse suggests that parents' generally positive hopes and desires for their disabled child's future may be accompanied by strong concerns about their child's generic position in society and likely challenges in adult life. Wolman *et al.* (2001), for instance, highlighted a fear of the child being teased or bullied in school, while Wolman *et al.* (2001) and Heiman (2002) emphasized concern about physical and financial independence in adulthood, the ability to acquire a profession or job, the availability of support services, having friends and establishing a family.

Russell (2003) asserted that potentially negative cultural and social values about disability were a particular concern. Beresford (1994) offered one possible explanation for this by suggesting that while society views disabled people in relation to their disability, parents see their child much more as an individual with strengths and limitations. Read (2000) has elaborated:

It can be argued that there is likely to be a gap between the mother's view of her child and the views of those outside the immediate household.

Other people's perceptions may often be governed by dominant and not very appreciative notions of disability and they may define the child primarily in those terms. For the mother who knows the child intimately, this simply does not square with her experience (p59).

3.6 Conclusion

This review has examined ideas framed by Bronfenbrenner's bio-ecological model. In relation to 'person'-related characteristics, medical and social models have been scrutinized, together with their dialectical representation in parents' perspectives, also a Vygotskian view of interaction between biological causes and responses of society which promotes or discourages development and learning. All three outlooks may help understanding of person-related characteristics of a young child with cerebral palsy.

In terms of 'context', two main strands of relevant policy-to-practice development have been discussed, the first the gradual move for children termed as having special educational needs and disabilities from specialist provision towards community-based, inclusive educational and early intervention support services, the second the growth of early-years provision for all children from birth to five, strengthened by agendas such as parental involvement, curriculum development and – for those with special educational needs and disabilities in particular – multi-agency working. The literature elucidates a 'patchwork' nature of provision (Bertman and Pascal, 2002), consisting of specialist and mainstream services, delivered in different ways at different geographic locations, the former including some which is less usual, such as conductive education.

In terms of 'process', Bowlby's and Ainsworth's attachment theories indicate how purposeful dyadic interactions between child and adult (usually the mother) may be key routes for stimulating the young disabled child's interest, activity and thus development. Dyadic becomes triadic when professionals – for instance, the Portage

worker or therapist – become involved. Triadic activities are then replaced with multi-person social environments which include peers and practitioners, as well as advisers and therapists. The contributions of these latter personnel may impact on how educational practitioners approach and support the disabled child.

The final notion of ‘time’ brings together person, context and process. In this study it does not encompass a wholly longitudinal dimension, but is seen as a forward-looking complement to the other three elements. The literature on parental desires and expectations, with particular focus on the child’s transitions, provides a pertinent snapshot of how a future relating to person, context and process may be viewed. A range of literature has suggested that parental belief in the child’s potential overlaps with concern about societal values, opportunities and continuing needs for support, creating both hope and uncertainty for those closest to the child.

Overall, Bronfenbrenner’s categories have provided structure and depth for consideration of pertinent issues. His emphasis on interaction and overlap between them (Bronfenbrenner, 1994; 1995) is also reflected in the review. For instance, when considering Vygotsky’s (1993) ideas about the disabled child’s development as ‘person’, discussion illuminated both context and dynamic interactions relating to process. Similarly, scrutiny of ‘time’ involved parents envisaging their child as a future ‘person’, as well as the contexts and processes which they thought necessary to meet future care and social needs. Amongst the themes emerging from this integrated scrutiny, three stand out for final consideration: multiple images of the disabled child, shared or strained purpose between parents and practitioners, and the duality of upbringing and education in the life of the young child.

Medical identity stems from the child’s neurological and developmental difficulties; social identity comes to the fore when opportunities or deficiencies of the early-

support system are interrogated. The child may have different professional input associated with each: health-related professionals, most notably therapists, addressing perceived deficiency in health or physical performance; early-years practitioners and other educators seeking to strengthen social identity within more generalized, inclusive, curriculum-driven environments. These two elements are brought together in most early-years settings, with the educational establishment becoming the platform also for specialist input, and with medical outlooks likely also to influence day-to-day thinking and practice of its education practitioners. Nevertheless, as suggested by Flewitt and Nind (2007) in the 'time' section, parents face difficult choices between scenarios where options may not fully reflect the images which themselves might construct about their own child.

Indeed, contextual issues create differences between perspectives which may affect the nature of stakeholders' cooperative working. On the one hand, there are personal parental perspectives, and on the other the policy-driven, or at least policy-influenced perspectives of practitioners, with their personal outlooks largely hidden or absent in the literature, as pointed out by Read (2000). Across these two outlooks tensions are likely between those based on deep experience with one disabled child (the experience of parents) and those based on wider but limited experience of a larger number of children (the experience of professionals).

Beresford (1994) and Read (2000) suggested a dichotomous relationship between parents and practitioners in this respect. Parents rely on professionals for services for their child – where these are seen as beneficial, then they may want more. They appreciate a positive professional attitude, constructive input and a helpful relationship. However, frustration may result when expected standards are not reached and anxiety arise when decisions about future provision need to be made. A further dichotomy is the fact that parents are provided by legislation with the idea that

they know most about the child, but then must hand over elements of their child's development and education to professionals who are seen to have greater technical expertise.

This relationship links to another interesting duality discussed in the first chapter, that between 'upbringing' and 'education'. One assumes in normal circumstances that upbringing is more the responsibility of parents, and education more that of professionals (Kraevskii, 2002). In the case of disabled children, however, boundaries are blurred: practitioners often enter the family home and may be concerned with a child's personal activities, such as development of self-care, for which parents would normally have full responsibility.

The literature has, therefore, provided an overview of specific issues related to the early life and development of children with disabilities in general and those with cerebral palsy in particular. Written academic discourse, however, may be somewhat distanced from the personal dilemmas which parents must themselves address in their relationship with their child, the efforts they make to address the implications of their child's disability and their aspirations for the future. From here, therefore, the focus of this study moves to the empirical investigation carried out to address such issues, seeking detailed clarification of perspectives of families and professionals, together with evidence of children's outlooks drawn from observation of their activities.

CHAPTER 4: METHODOLOGY

4.1 Introduction

The study now proceeds to discuss methodological issues, such as design, research approach, sampling strategy, data collection and analysis. The chapter also outlines steps taken to strengthen validity, reliability and trustworthiness of the investigation and the ethical considerations and moral challenges encountered. Finally, some reflective points are examined regarding the role of the researcher.

4.2. Design

The rationale for adopting the bio-ecological model to inform and frame the investigation, including research questions, was discussed in Chapter 2. Its all-encompassing features also helped development of empirical aspects of the study.

4.2.1 Approach

The research questions required a predominantly exploratory and interpretive approach to provide ‘understanding with deep insights’ (Newby, 2010, p134). For methodology, appropriate means needed to be found to progress the study from description to exploration, then to more intricate and comparative explanation, so that the complexity and interrelated nature of the research questions could be exposed. This task was seen more as a methodological problem-solving challenge, than as an epistemological choice (Newby, 2010).

Traditionally, this kind of issue in educational research would have been resolved by drawing on one or other research paradigm – positivism or interpretivism – and selecting investigative tools which emerge from their alignment with particular worldviews (Patton, 2002; Pring, 2004; Robson, 2011). Epistemological considerations – such as belief in single or multiple realities, deduction or induction to obtain knowledge, interpretation through logic or creativity, the nature of the researcher's position during data collection and analysis – would have been the grounds for making decisions about whether to use a quantitative or qualitative research design.

However, recognition of the complementary nature of these approaches has given rise to fundamentally different perspectives about design of real-life research (Pring, 2004; Creswell, 2009; Thomas, 2009; Denscombe, 2010; Newby 2010). This has become more of a pragmatic concern, rather than a commitment to specific, philosophically driven assumptions. Typologies of different approaches or paradigms are accepted, but not regarded as 'articles of research faith to which [researchers] should adhere' (Newby, 2010, p127). Studies which take this pragmatic stance tend to combine research methods, challenging the traditional quantitative-qualitative dualism, advocating the compatibility of different data-collection methods and producing both numerical and qualitative data (Pring, 2004; Thomas, 2009; Creswell, 2009; Blaxter *et al*, 2010; Newby, 2010; Muijs, 2011). Data collection, therefore, might include 'multiple methods of data and multiple forms of analysis' (Creswell, 2003, p208), articulated and applied in distinct, explicit procedures. This more contemporary view acknowledges the co-existence of opposing views in real-world research; combining and integrating data delivers understanding in a workable, practical fashion (Newby, 2010).

An approach of this kind in this study first involved quantitative scrutiny of broad tendencies and patterns, then use of the understanding gained to explore qualitatively the views and experiences of stakeholders. This sequential approach, as described by Creswell (2009), helped to address and understand different dimensions of the research issue.

A combined approach also made it possible to address all aspects of Bronfenbrenner's model, including the mesosystemic overlap and interplay between elements. While individual experiences were at the heart of the study, their pertinence – how and why things happen – could only be understood by comprehending broader, inter-related circumstances. The linking of methods also supported triangulation, an important benefit of using combined-method strategies (Denscombe, 2010; Newby, 2010; Blaxter *et al*, 2010; Robson, 2011). Although findings from qualitative and quantitative elements could not validate each other, their complementary use helped to confirm the 'correctness of the insight and the legitimacy of interpretation' (Newby, 2010, p129).

Overall, the desirability of this pragmatic approach arose from its potential to obtain data from which to produce a fuller and more complete picture of the phenomenon (Blaxter *et al*, 2010; Denscombe, 2010). However, employing it was not a simple matter of picking and mixing qualitative and quantitative data-collection tools. Blending methods needed critical rationalization and careful planning to ensure that findings emerging in different forms led to enhanced understanding about the phenomenon being studied (Denscombe, 2010). The procedures and principles applied to each type of data-collection method will be explained later in this chapter.

4.2.2 Case study

There are many strategies from which exploratory investigation of this kind could have been developed, described, for example, in Gomm *et al.* (2000), Ritchie (2003), Simons (2009) and Robson (2011). However, the interactive nature of the research questions, and within this the particular interest to expose and interrogate multiple perspectives, including children's experiences, gradually steered the design towards a case-study strategy which could 'illuminate the general by looking at the particular' (Denscombe, 2010, p73) and help to avoid 'misfits' when another strategy might be more beneficial (Yin, 2009).

In Stake's (2005, p444) definition, 'a case study is both a process of inquiry about the case and the product of that inquiry'. The case is a 'specific, complex, functioning thing' (Stake, 1995, p2), to be examined as a 'singularity' (Bassey, 1999, p47) or studied as a phenomenon (Swanborn, 2010). Case studies have many commonalities with other empirical designs (Stake, 1995), yet their attributes, in particular the idea of a distinct focus and use of multiple methods, make it a powerful design strategy to investigate a 'contemporary phenomenon in depth and within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident' (Yin, 2009, p18).

Nevertheless, much critical comment in the literature focuses on fuzziness and uncertainty about what constitutes the approach (Hammersely and Gomm, 2000; Opie, 2004). Hammersley and Gomm (2000, p2) argue that 'the case study is not a term that is used in a clear and fixed sense'; Blaiki (2010) considers it to be an 'umbrella term' (p188), suggesting a continuum of ways it may be used in enquiry. In defence of such criticism, Stake (2005) provides an epistemological rationalization and argues that a case is to be studied for its potential to develop understanding –

methodology should therefore create optimum circumstances to deepen this understanding. Swanborn (2010) further emphasizes the necessity to explore the phenomenon rather than focus on the research participants. The researcher's interactions with these participants are only the medium through which understanding of the phenomenon emerges.

In this study such defining characteristics only became evident as the parameters of the study developed. 'Boundedness', a pertinent element in case studies (Stake, 1998; 2005; Creswell, 2009; Yin, 2009; Simons, 2009), emerged from the clearly defined focus of the study reinforced by Bronfenbrenner's PPCT model. This focus incorporated pre-school children:

- a) under the age of five;
- b) who had been diagnosed with cerebral palsy;
- c) who were the recipient of early educational and childcare provision of some kind;
- d) who lived in the target local authority.

To achieve in-depth, integrated understanding across the PPCT model, Yin's (2009) rationale of identifying explicit units of data collection for analysis at each level was applied. Six such units were embedded in the study. Table 4.1 provides an overview of these, together with the sample involved and the nature of data obtained. This approach allowed engagement with the research questions in progressively increasing detail, gradually moving from descriptive analysis of outlooks to explanation and comparison between perspectives. Accordingly, this multi-unit and multi-method approach addressed the frequently cited requirement that a case study should be an in-depth investigation (Stake, 1995; Yin, 2009; Simons, 2009; Robson, 2011).

	Samples	Method of data-collection	Numbers	Nature of data
1.	Parents of children with cerebral palsy	Questionnaire survey	Distribution: 72 Returned: 50 Return rate: 69%	Mainly quantitative, some qualitative
2.	Practitioners working with these children in early-years settings or as part of specialist support services	Questionnaire survey	Distribution: 186 Returned: 85 Return rate: 46%	Mainly quantitative, some qualitative
3.	Managers of local-authority support services	Semi-structured interviews	3 interviews representing 3 local-authority services (2 individual interviews; 1 with 2 interviewees)	Qualitative
4.	Selected parents of children with cerebral palsy	Semi-structured interviews	6 interviews (3 individual interviews with mothers; 3 joint interviews with mother and father)	Qualitative
5.	Practitioners working with these children in early-years settings or as part of specialist support services	Semi-structured interviews	7 individual interviews	Qualitative
6.	Target children's observed experiences	Observations	6 children observed, 11 observation sessions	Qualitative

Table 4.1: Units of data collection for analysis: samples and methods

Stake (2005) makes a distinction between different kinds of case studies, related to the investigation's purpose and focus. In Stake's terms, the intention to gain deeper and more contemporary insights into an everyday phenomenon made this investigation an 'instrumental case study', whereby 'a particular case is examined mainly to provide insight into an issue ... it facilitates our understanding of something else' (p445). This 'helps us to pursue the external interest' (p445), rather than any distinct, inherent interest peculiar to the case. Analysis within and across units provided opportunity to 'capture the circumstances and conditions of everyday or commonplace situations' (Yin, 2009, p48), rather than simply to study perspectives and experiences for their unique characteristics.

One commonly agreed limitation of case studies relates to generalization, in that it is not seen possible to generalize from a single case in ways which might influence public and academic understanding (Gray, 2004; Simons, 2009; Yin, 2009). This potentially leaves the reader uncertain about the extent which findings from the case study might be applied elsewhere (Yin, 2009). However, it has also been broadly recognized that a case study does not intend to generalize to a larger population.

Indeed, this study does not offer findings of this kind. Instead, it creates opportunity for a 'vicarious experience' (Stake, 2005, p454), giving readers the opportunity and responsibility to reflect on, transfer, apply or reject aspects of findings. This process may influence readers' 'awareness and understanding', thus providing 'naturalistic generalization' (Stake, 1995, p454) on a theoretical level, especially if outcomes are in harmony with the reader's own contextual and personal experiences (Swanborn, 2009).

4.3 Sample

Data collection for the study took place between April 2011 and September 2012 in a local authority in England. This authority was selected using the researcher's own professional contacts, a process commonly described as convenience sampling (Robson, 2002; Newby, 2010). According to the 2011 census (Office for National Statistics, 2013), the authority is largely urban; within its growing population of 300,000, nearly 90% is white British, the next largest group being Asian and British Asian. Unemployment in the local authority is higher than the national average.

Within this local authority, support for children with disabilities and their families involved three service departments – explanation of their roles is part of data

presented later in this study. One of these held the authority's voluntary disability register, from which some demographic information was shared with this researcher to help estimation of the legitimate population for the study. This population was identified as:

- a) All children with a diagnosis of cerebral palsy, under the age of five at the time of data collection, living within the geographic boundaries of the chosen local authority and receiving either home-based or setting-based input from early-years and childcare providers;
- b) The parents or guardians of these children;
- c) Practitioners working in setting- and home-based provisions offering early education and childcare for the above children and their families and located within the local authority;
- d) Heads of educational and other support services of local-authority departments with responsibility for supporting these children and their families and for providing professional services at the above settings;
- e) Other educational services not located within or managed by the authority, but providing authority-funded placements for these children.

In ideal circumstances, probability sampling would have been the most valid strategy to select the specific data units from this population. Robson (2011) suggests, however, that this approach is not always appropriate for research, and indeed for two reasons this option was not suitable for this study. First of all, no combined and comprehensive population list was available from the authority from which an appropriate sample could have been identified. Secondly, the research questions demanded in-depth information, emerging from examination of a single phenomenon under different circumstances (Swanborn, 2009). Establishing the sample on the grounds of statistical logic within such a small eligible population would have missed

or compromised the opportunity to display those differences and similarities amongst the social units which formed the basis of the study.

Non-probability sampling was therefore applied to optimize the opportunities to obtain relevant, rich and illustrative data to answer the research questions (Patton, 2002; Simons, 2009; Robson, 2011). Sample units were identified on the grounds of their particular roles and responsibilities relating either to children or to the broader support system in which early-years input was provided. Due to the small and limited population size, all eligible parents and practitioners were asked to take part in the surveys. Similarly, all three key personnel with strategic responsibilities for implementing national policy within the local authority were invited to contribute to interviews. Finally, children, their parents and their practitioners were selected for observation and interview so as to represent variety in children's ages and the types of early support being received, and to reflect diversity of experience in different early-education and care provisions. Non-probability or purposive sampling, as described by Robson (2011), was therefore sought by 'choosing cases to illustrate a wide range of the dimensions of interest' (Coe, 2012, p49), aiming for maximum variation (Morse, 1998; Coe, 2012).

Establishing contact with the local authority's three service departments was essential for these sampling processes. Information about settings, practitioners, families and children was collated from these services. The population frame which emerged may, however, have been imperfect, a possibility examined by Kish (1965) in Curtis and Curtis (2011). For instance, the actual eligible population might have included missing cases (those who did not appear on caseloads), duplication of cases (those on more than one caseload), or foreign cases (for example, children who had not yet been diagnosed with cerebral palsy or who had another diagnosis). Nevertheless,

negotiation with the three services made it possible to identify participants from the population criteria.

4.4 Methods

Quantitative and qualitative data was accessed from a range of sources and in a range of formats: semi-natural settings through questionnaire surveys and interviews, and natural social settings through observation. Examination of the phenomenon was therefore made, in terms of Blaikie (2010), both *in situ* and by interrogating research participants' interpretations of situations. The subsequent sections of this chapter give a rationale for each data-collection method.

4.4.1 Survey

The first part of the study's bio-ecological examination of multiple outlooks involved two small-scale, cross-sectional surveys. These explored the attributes of stakeholders – parents and practitioners – such as their backgrounds and experience, and subsequently and more prominently their attitudes to supporting the early development and learning of young children with cerebral palsy. These surveys provided a bridge between different levels of scrutiny, coming after the examination of national outlooks in the literature review, but acting as a precursor for the more in-depth, more qualitative aspects of the empirical enquiry. Exploring generally held outlooks in the surveys also helped to inform the setting-based and individual perspectives and experiences collected in later parts of the investigation.

Robson (2011) describes surveys as non-experimental, quantitative data-gathering methods with a fixed design, particularly suitable for describing specific, but limited

dimensions of a phenomenon by obtaining data from a large sample. Muijs (2011) sees them as both commonly used and flexible in implementation. The central advantage of the surveys for this study related to their potential to reveal respondents' multiple social constructs – beliefs, attitudes and opinions – in a standardized format (Blaikie, 2010; Muijs, 2011; Robson, 2011). Such standardization allowed naturally occurring attributes and attitudes, latent variables which in everyday life do not exist in numerical form, to be translated into numerically analysed and statistically articulated data (Muijs, 2011).

Originally, it was anticipated that just one survey could be designed for both parents and practitioners to complete, enhancing possibilities for standardization. However, due to diversity of experience and responsibility between the two groups, this proved too problematic. Consequently, two separate questionnaires were developed, including some questions which were the same in both and others which were differentiated according to parental or practitioner roles (Appendices B and C).

Each survey questionnaire was made up predominantly of closed questions. These asked respondents to select answers from lists of pre-defined categories. Some open-ended questions or comments sections were also included, giving respondents opportunity to construct their own responses. However, these were kept to the minimum to avoid data analysis becoming too complex (Muijs, 2011; Robson, 2011).

The majority of questions on attitudes used rating scales, where respondents were asked to indicate the strength of their opinions on particular issues. A neutral option, indicating 'Don't know' or 'Neither agree or disagree', was included in these scales. This was located as the last option in the row in response to the warning from Muijs (2011) about the threat to validity which a middle position can pose if respondents are unsure of their position.

Another issue addressed at the design stage of the survey was that of positive response biases. As described by Muijs (2011), this is when respondents select the option which they feel to be the most favoured or desired by the researcher. To reduce this threat, some attitude questions had further emphasis, such as asking respondents themselves to pick out from a range of possible factors those most reflective of their opinions and experience and to make comments on these.

Prior to conducting the surveys, it was necessary to tease out further potential difficulties with design (Muijs, 2011). This was done by conducting a pilot study with three parents and six professionals in another local authority. The pilot respondents were asked not only to complete the survey, but also to comment on the time this required, the clarity of questions and difficulties in answering them. As a result of feedback, parental questionnaires were changed to add the option of grandparents as possible respondents. One practitioner respondent suggested re-phrasing some questions so they could be more easily answered by those with experience only of one child with cerebral palsy, as well as by those with experience of many. As a result two questions were amended in the survey. Otherwise pilot respondents found the questionnaire easy and quick to complete and analysis of their responses indicated no ambiguities in the questions being asked. The final survey was then drawn up.

Questionnaires were distributed to relevant parents and practitioners either by post or personally; return of the questionnaires was also conducted this way. To increase the credibility of the questionnaires and to address the danger of a low response rate (Muijs, 2011; Curtis and Curtis, 2011), either the head of the provision or another designated person was asked to distribute them to parents and to practitioners working there. This request was reinforced by a further telephone call from the researcher about ten days later.

The response rate for both surveys showed a varied picture. In some settings no questionnaires were returned, while in others all were completed and given back. The overall response rate for the parental survey was 69%; for the practitioner survey it was rather lower: 46%.

4.4.2 Interviews

To obtain detailed and integrated data, findings of the surveys needed to be triangulated against more in-depth qualitative data from other sources. Interviews provided the relevant opportunity to gain such data through closer, personal interaction with research participants (Schostak, 2005).

Interviews are commonly perceived to be strategies for revealing characteristics of a phenomenon which cannot be accessed or observed directly by the researcher (Patton, 2002; Gray, 2004). In this respect interviews for this study were designed to gain understanding from a variety of stakeholders: professionals implementing national policy at local-authority level; practitioners enacting national and local-authority procedures within settings in direct, practical contact with the children; and parents who were the service-users of such provisions and who could provide the most detailed insight into their child and her or his needs. Altogether, 17 interviews were conducted; Chapters 7, 8 and 9 provide a breakdown of the roles and backgrounds of each set of interviewees.

Due to their interactive characteristics, Robson (2011) perceived interviews to be an illustrative data-collection tool, with the capacity to reveal extended or even unexpected information, a 'journey into another's perspective' (Mears, 2012, p171). Indeed, the face-to-face interviews in this study provided opportunity to discover stakeholders' professional or personal opinions and experiences, teased out by

careful questioning, prompting and probing, as described by Drever (1997). Verbal interaction, co-reconstruction of past events and experiences, perceptions about the current *status quo* and exploration of aspirations and desires for the future all helped to capture outlooks on the nature and appropriateness of early support for these children. A central benefit was participants' individual interpretation of the same phenomenon, as outlined by Rubin and Rubin (2012). Richness of data emerged from interviewees' specific stakes in the overall support system, their personal and professional values and their connections with the children. The interviews were also an effective way of elaborating, extending and challenging perspectives obtained by other methods.

To utilize their advantages in terms of data collection, the interviews required thoughtful preparation, keeping the research questions in mind (Gray, 2004, Robson, 2011). In all cases the aim was to establish a guided conversation, stimulating depth of discussion while maintaining its orientation (Flick, 2011). Design also needed to take into account interviewees' particular backgrounds and roles, addressed by drawing up separate interview schedules for the three involved groups: local-authority personnel, parents and practitioners.

Schedules for interviews with local-authority personnel explored procedures and practices relating to young disabled children in general and elicited their particular relevance to children with cerebral palsy (Appendix D). Discussion included examination of how national policy was implemented in the authority and reflection on this implementation. The use of both open-ended and semi-structured questions aimed to trigger the depth recommended by Flick (2011).

Interviews with parents focused on their unique experiences, feelings and desires, the kind highlighted in Read's (2000) research with mothers of disabled children. These

perspectives emerged from parents' attachment to their child, their responsibility for his or her upbringing and their involvement with a range of professionals within the overall support system (Read, 2000). To capture these perspectives, interviews had to enter quite personal worlds, involving recall of both positive and negative events. Discussing such private, possibly sensitive scenarios needed a subtle approach, making it possible to gain pertinent and in-depth data in an ethically appropriate way.

Except in the case of single-parent families, these interviews were offered as paired events, involving both mother and father, and this opportunity was taken up by all dual-parent families. This had a number of benefits, reflecting some common advantages of group interviews or focus-group discussion described by Robson (2011). For example, paired interviews provided opportunity to lessen the possibly unsettling nature of questions – the participants may have felt more empowered to answer them by being together (Robson, 2011). Indeed, the distinct feature of the interviews was not the interviewees' interaction, as Flick (2011) suggests is usually the case, but more the opportunity to prompt each other to recall experiences and to enrich subjective reconstructions or reinterpretations of events. The situation also emphasized the shared roles of mother and father in upbringing and the roles each may have taken in their child's everyday activities and in relationships with practitioners.

Apart from this kind of affinity, there were also potential disadvantages in doing paired interviews which might have been anticipated prior, during and after data collection. Newby (2010) identifies several potential difficulties with multi-person interviews, for example interviewees' unwillingness to reveal their opinions in front of the other person, and imbalanced commitment from participants to the interview. In this study, the clearest consequence of interviewing both mothers and fathers was the potential power imbalance between interviewees if one person sought to dominate the

discussion (Bashit, 2010; Newby, 2010). To minimize the risk of this undesired consequence, the researcher needed to focus on maintaining dynamics between the two interviewees (Newby, 2010), respecting and responding to each participant's views, encouraging shared discussion, and following up both fathers' and mothers' lines of thinking as these developed.

Regardless of whether parental interviews were paired or individual, they became 'episodic interviews' (Flick, 2011, p115), carried out with the assumption that perspectives were embedded in real-life events and scenarios which were time-limited or on-going. Discussion of experiences allowed parents not only to reveal their values and attitudes, but also to elucidate opinions, tensions and desires arising from their roles as advocates for their child (Read, 2000). Therefore, in parental interviews, as with practitioners, the schedule included open-ended questions and narrative opportunities through which to capture illustrative data representing their subjective outlooks (Appendix E).

The third set of interviews, those with practitioners, were designed more with interviewees' direct, context- or child-specific experiences in mind. As with parents, these participants could draw on practical scenarios and examples while answering questions (Appendix F). Their interviews had more flexibility than those with local-authority personnel, with professional narratives also included in the design, as suggested by Drever (1997), enriching the data.

In contrast with the survey questionnaires, the original intention was to separate these last two sets of interviews into 'personal' and 'professional', the former being those with parents, the latter with practitioners. However, as they were carried out, a more combined format emerged. Some parents had relevant professional roles and these influenced their opinions. With practitioners the reverse applied – they were often

parents themselves and their personal perspectives were seen to impinge on their professional views. This unexpected feature – a blending of roles – became an interesting issue when interpreting interconnections between different stakeholder groups.

As with the questionnaires, piloting of interviews was needed in order to convert the interview design into working reality (Robson, 2011). Testing the questions to be asked, then checking the feasibility of schedules, techniques and practicalities, helped to create optimum conditions for the real events (Drever, 1997). Piloting took place in another local authority with participants who had similar roles to those of interviewees in the actual study.

Two main issues were raised for consideration as a result. First, it was recognized that in order to utilize the potential of interviews to provide exploratory rather than descriptive data, interviewees needed to be prompted or even challenged more often by the researcher to extend their responses (Rubin and Rubin, 2012). This attribute improved as the actual interviews progressed, as Drever (1997) suggested. The second and more influential issue related to the researcher's background of work with children with cerebral palsy, parents and practitioners. This experience crept into conversations, in the form of researcher bias (Aubrey *et al*, 2000; Simons, 2009; Robson, 2011), especially when interviewees shared dilemmas or challenges which it was tempting to help to resolve. It was essential to recognize that although the researcher was an 'insider' in relevant subject areas and understood the issues and examples brought up by the participants, for a trustworthy, and indeed an ethically sound investigation, this role had to be diminished. Instead, the researcher had to become an active, objective listener (Simons, 2009), sympathetic certainly, but not a commentator on issues.

One disadvantage of this data-collection method, highlighted by Robson (2011), was that negotiating, conducting and transcribing interviews proved time consuming, delaying the time when subsequent, related observations could begin. A further complication was that although interviews preceded observations in the data-collection sequence, in order to address the research questions the interview sample had to be matched with the sample for observations, that is, interviews had to be with parents and practitioners of children who would later be observed. This required substantial co-ordination in order to reach agreement with parents, practitioners and heads of settings about who might be involved in both data-collection methods. However, the advantages of engaging in interview discussion with stakeholders before observing the child with whom they were concerned outweighed these difficulties.

4.4.3 Observations

Whereas the previous methods interrogated similarities and contrasts in outlooks of different stakeholders, observations were employed in this study in order to capture the manifestation of such perspectives in children's natural experiences. Observations are generally perceived in this respect to be an effective and versatile tool for interrogating real-life practices and apprehending the characteristics of everyday situations and scenarios (Simpson and Tuson, 1995; Robson, 2011; Clough and Nutbrown, 2012).

In this study they gave the opportunity to explore another dimension of an intricate social reality, captured this time more from the child's point of view. They had a highly contextual purpose, serving to interrogate the interplay between the child and his or her immediate social and physical environments, data not obtainable directly by other methods of collection. Observations also became a tool to validate stakeholders' perspectives expressed in the survey and interviews (Frazer, 2004, Simons, 2009), as

well as creating a platform for discovery of new ideas and issues not highlighted previously.

Furthermore, observation made possible a more balanced, fairer and ethically more sound research design, one in which children themselves became research participants, as well as the adults who surrounded them. Although indirect, children's involvement gave them some kind of voice, as recommended by Lloyd-Smith and Tarr (2000) and France (2004), in a situation when other, more direct methods, such as interviews, would present ethical and practical challenges, described for instance by Frazer (2004), Opie (2004) and Simons (2009). As argued by France (2004), observing children's interactions with others positioned them as 'social subjects' rather than 'objects' (p179) of the study. Capturing and interpreting children's perceptions of social scenarios and more specifically their perceptions of and responses to situations led by others provided opportunity to reveal their own opinions and feelings, for instance about influence of the physical environment, social and educational expectations, support mechanisms and the means by which their wishes and desires were taken into consideration by others.

The sample for observations aimed to reflect the multi-contextual nature of early support within the local authority. Children were chosen because of the different forms of early-years education and childcare provision they attended, all of which were available to families with young children with cerebral palsy living in the authority. Overall, observations were conducted of six target children, each in one of six different kinds of early-years provision. This range also enabled exploration of various support options available for children up to the age of five.

To make use of the above benefits, appropriate conditions and strategies for observation needed to be in place. These included the need to determine the nature

of the researcher's presence and the extent to which the focus of what was to be observed was predefined in observation schedules. To make these decisions, both methodological and ethical issues needed to be considered.

Emerging from ethnographic or exclusively observational research is a degree of common agreement that researchers who take up what Patton (2002) calls an 'emic' or insider position intend to immerse themselves into the context being observed. Being an operational part of the social activities under scrutiny gives researchers a role in that activity, which in return helps them to develop understanding from shared experience with those being observed (Patton, 2002).

While methodologically participant observations of this kind might have helped in some circumstances, in this research anticipated pedagogical challenges outweighed possible benefits of that approach. Involvement of the researcher would have inevitably impacted on the routines, activities and reciprocal interactions which were the focus of observation. That possibility was seen as both pedagogically and ethically unacceptable, as suggested by Robson (2011), and could have had undesired implications for the nature and quality of the collected data.

The intent to capture with minimum interference what was going on lent itself more to an 'epic' or outsider position (Patton, 2002). To fulfill this role, observations were carried out without actual participation in the activities. The observer's status, both in settings and at the child's home, where visits and observations by professionals are common occurrences, was therefore what Robson (2011) identifies as simply another role amongst others. Taking this stance helped the researcher to remain inconspicuous, as recommended by Sylva *et al.* (1980), and made possible the capture of detailed data, perhaps also increasing the chances of making new discoveries (Thomas, 2009; Robson, 2011).

At an early planning stage, it was thought likely that unstructured observations would be the most effective way to obtain detailed data. This approach is recommended by Thomas (2009), who with others conducted research on supporting physically disabled learners in mainstream settings (Thomas *et al*, 1998, in Thomas, 2009). According to his recommendations, taking unstructured records facilitates thick description of events and behaviour of a kind not achievable in other ways.

In this study, however, piloting an unstructured strategy highlighted drawbacks derived from the lack of a specific agenda, in particular a tendency towards researcher bias, a commonly acknowledged concern with this kind of approach (Simpson and Tuson, 1995; Denscombe, 2010). Observation notes, as well as debriefing with practitioners after observation had taken place as recommended by Aubrey *et al*. (2000), revealed evaluative comments which seemed on reflection to emerge from the researcher's own pedagogical outlooks on supporting young children with cerebral palsy, rather than from more objective approaches to the data. While Thomas (2009) regarded such 'comments and interpretations' (p188) as advantages, in this study they were seen to be a risk to quality. Furthermore, cross-checking notes with practitioners indicated another common threat, that identified by Robson (2011) of being selective about which scenarios and events are captured and recorded.

Eventually, therefore, a semi-structured form of observation was adopted, enabling 'both looking *at* and looking *for*' (Clough and Nutbrown, 2012, p59, italics in the original) and achieving a clearer focus on what to observe and how to make note of it (Simpson and Tuson, 1995). An observation framework from Sylva *et al*. (1980), originally designed to record young children's interactions in early-years settings, proved to be a helpful model, as it provided a structure and focus, as well as opportunity to make records in a rich, detailed and illustrative fashion (Appendix F).

The schedule which was developed first provided opportunity to describe the social and physical environment. It gave information about the child's overall position in the setting and indicated how the provision accommodated the child's needs in general terms. The main part of the observations then focused on capturing the context and nature of reciprocal interactions between the child and practitioners in an open-ended, detailed fashion. The schedule allowed the ways in which children were facilitated in their attempts to succeed with their actions, as well as the instances when practitioners seemed not to respond to the child's needs in this respect, to be recorded in consistent but flexible ways. The schedule proved suitable for observation in both setting- and home-based provisions.

In all provisions observations were conducted of different activities throughout children's usual routine. This was imperative for understanding the continuity and consistency of practitioners' expectations and interactions and to reveal to what extent and in what ways they proactively provided support. Evidence was also gained of the ways in which this support influenced the child's behaviour and participation, whether practitioners kept in mind the child's needs as a whole or focused on particular aspects and devoted less attention to others, and whether interactions and support were oriented more towards completion of tasks by any means or towards the child's own independent activity. Observations carried out in the child's home focused on times when a practitioner was present, including occasions when practitioner and parent had a discussion or briefing. Chapter 10 provides an overview of the number and length of observations undertaken.

All observations took place after interviews with relevant practitioners and parents had been completed. This sequence had two benefits. Firstly, it provided opportunity to explore the interplay between stakeholders' perspectives as expressed in interview on the one hand and children's observed experiences on the other. Secondly, this route

allowed child and adult participants to become used to the researcher – this may have helped to reduce a possible ‘Hawthorne effect’ (Aubrey *et al*, 2000), whereby changes of behaviour may occur simply as a result of being observed (Simpson and Tuson, 1995). To diminish this possibility further, the introductory visit and other communications prior to and following each observation were designed to be very professional and reassuring in nature, perhaps helping the researcher to play a more natural role in the setting (Robson, 2011) and others to remain at ease in their everyday roles and behaviour.

4.5 Data analysis

To summarize, data gathering took place within the study’s case-study strategy using a multi-method and multi-contextual orientation to develop an in-depth and holistic understanding of the phenomenon (Yin, 2009; Simons, 2009). Data was obtained, analysed and interpreted in the form of distinct data units (Yin, 2009), in a mainly quantitative to qualitative sequence (Creswell, 2009). This approach helped to move interpretation forward by tackling both the scale and depth of the research questions (Denscombe, 2010).

Bronfenbrenner’s (1979) bio-ecological structure was used in analysis. Within each data unit, therefore, four broad categories were established: information related to the child, to the particular contexts under investigation, to the processes of early support, upbringing and education, and finally to stakeholders’ ideas about the future. Although Drever (1997) warns about the danger of distorting qualitative data with such an approach, it was felt that this kind of categorization did not limit discovery, but rather enabled the researcher to begin to make sense of sometimes excessive and rather jumbled data in a systematic and logical fashion.

Prior to analysis and interpretation, data sets required thoughtful preparation in the form of data reduction. For the quantitative survey this meant turning textual information into numbers (Creswell, 2009; Muijs, 2011), reflecting pre-defined categories set out in the survey questions. Qualitative data from interview and observation records was prepared for analysis by identifying pertinent issues and themes (Aubrey *et al*, 2000; Denscombe, 2010), then grouping or weeding these out for the purpose of 'formulation of the story of the case' (Flick, 2012, p150). This process involved coding, a commonly accepted and broadly applied strategy, which according to Flick (2011, p148) serves to 'classify expressions... in order to attach annotations and "concepts" ... to them' and which according to Janesick (1998) facilitates interpretation of complex information.

Actual analysis of the quantitative data then involved the use of SPSS.16©, statistical software commonly employed in educational research (Muijs, 2011) due to its capacity to carry out both simple and more complex calculations. In this study, because of the nature of the research questions and the investigation's sampling strategy, such analysis was limited to obtaining descriptive statistics (Blaikie, 2010) and not concerned with more complex predictions relating to a larger population for which surveys are often employed. Strategies used therefore included frequency counts and the seeking of association between variables (Blaikie, 2010; Muijs, 2011; Curtis and Curtis, 2011).

Interrogation of qualitative data was more concerned with open-ended construction of meanings and understandings (Creswell, 2009; Robson, 2011) from the coded data. This process involved allocating concepts to particular elements of the PPCT model, then within each of these broad categories establishing further themes reflecting concepts in the literature and from the data itself.

To answer the research questions effectively, understanding which emerged from the various data units needed to be integrated to produce more holistic and in-depth understanding of the phenomenon as a whole (Yin, 2009; Simons, 2009). By using triangulation as a 'heuristic tool' (Janesick, 1998, p47), it became possible to bring together the findings through reflection on the quantitative and qualitative elements, resulting in a more balanced and complete picture (Flick, 2011; Robson, 2011). Analysis and interpretation also had to comply with expectations relating to trustworthiness and to ethics, explained in this chapter's final sections.

4.6 Validity, reliability and trustworthiness

Some issues related to the strengthening of validity, reliability and trustworthiness of data have been scrutinized earlier in this chapter. This section addresses such issues in more detail, highlighting distinct ways in which they were addressed in quantitative and qualitative aspects of the study and in the research as a whole.

Validity is commonly defined as 'whether an instrument measures what is intended to measure' (Coe, 2012, p41), suggesting a legacy of quantitative research in which credibility depends on the presence of objectivity, consistency and replicability (Roberts-Holmes, 2005). Others explain validity in relation to other attributes, such as research being democratic (Simon, 2009), truthful (Mukherji and Albon, 2010) or thorough and honest (Robson, 2011), ideas with features of qualitative research design and interpretation more prominently in mind.

In this study, with its combined-methods design, both lines of thinking had to apply. While it was not possible with either parts of the combination to achieve full validity

(Robson, 2011), it was felt that credibility and quality could be increased, both in the design of methods and when interpreting collected data.

Internal or content validity was addressed in the quantitative survey by considering Muijs' (2011) assertion that designing and employing objective measurement tools ensures the 'appropriateness and meaningfulness of inferences' (Aubrey *et al*, 2000, p56). This critical issue was addressed at the planning stage by using piloting to design out common threats to validity in surveys, such as ambiguities of instructions or of questions themselves, and positive response biases (Muijs, 2011).

External validity concerns the extent to which findings from a study can be generalized to a larger population. However, in the survey, with the use of non-probability sampling and the application of only simple descriptive statistics, findings were not intended or not suitable for making predictions to other contexts (Janesick, 1998; Muijs, 2011). Instead, the survey aimed to identify tendencies within the data in order to highlight relationships between stakeholders' backgrounds, opinions and values which might be of interest or relevance to others, if not fully applicable to them.

Concern for validity in the larger, qualitative aspects of the study was demonstrated by applying strategies related more to trustworthiness of data gathering and interpretation. This concept, originally introduced by Lincoln and Guba (1985, in Aubrey *et al*, 2000), covers a range of tactics, all of which aim to strengthen confidence that an investigation addresses the objectives set by its research questions. In this study these tactics included the use of multi-method data gathering, purposive sampling (and within this maximum variation), transparent piloting, data checks with research participants and monitoring of the role and impact of the researcher at design, data-collection and interpretation stages of the enquiry, as described by Robson (2011).

Triangulation played an important role in increasing the accuracy and quality of findings of the overall study (Schostak, 2002; Gray, 2004; Robson, 2011). This feature provided ongoing opportunity in the research to represent the multiple voices of various stakeholders, including – as far as was feasible – the children themselves. This became possible by cross-checking findings from various data-collection methods, as well as by contrasting the perspectives expressed by the range of participants. Triangulation, as described by Robson (2011), therefore highlighted similarities, contrasts and even contradictions with the overall data and facilitated the process of making discoveries in a more trustworthy fashion.

The study also needed to consider the issue of reliability, which according to Mukherji and Albon (2010) concerns the extent to which data collection and analysis give consistent results when repeated on different occasions, what Punch (2003) describes as a stability of findings. In its design, the study sought this through careful preparation and transparent explanation of procedure. This meant that its design could be replicated, but insights and discoveries emerging from the repeated research would be unlikely to be the same (Scaife, 2004).

4.7 Ethical considerations

This study dealt with a particular area of public interest. Ethical issues therefore emerged from the need to promote and protect the professional and personal integrity of participants, to represent their interests respectfully, and, as Simons (2009) suggested, to show a sense of obligation to the research community. Concern to address such considerations meant that ethical considerations had to ‘weave into all parts of the research fabric and shape the methods and findings’ (Alderson, 2004, p110).

Moral contemplations in this study were therefore considered as situated activities (Simon, 2009), manifested in 'growing concern with the ethical dimension of planning and implementing research' (Oliver, 2003, p3), rather than as mechanical application of certain obligations at particular stages of the enquiry. Although particular principles were relevant, such as those listed by BERA (2011), these needed to be operationalized and extended in relation to particular aspects of the investigation.

A broad range of ethical deliberations applied. These included issues of informed consent; the avoidance of harm and negative experiences amongst participants, including those from vulnerable groups; respect for their choices and voices; and making their contribution to the study a positive, even beneficial experience.

Informed consent clearly has two elements: 'Consent must be given, and it must be informed' (Lindsay, 2002, p12). The latter involved not just sharing technical aspects of data collection, but also, more importantly perhaps, nurturing a 'co-operative relationship between the researcher and the participant' (Oliver, 2003, p31). As a pre-requisite for voluntary participation in the research it was pertinent to ensure that local-authority representatives, parents and practitioners appreciated their roles and rights and felt assured that their contributions would be handled fairly, confidentially and in an anonymous manner. For this, extended written information was provided, then reinforced through telephone conversations, preliminary visits and further contact during and after data collection. Formal consent was then sought from all adult participants and any 'gatekeepers' professionally responsible for them – this was given in writing, as an email message, during a telephone conversation or personally face-to-face.

As the study involved young children, albeit indirectly, the consenting process had to apply to them also (Oliver, 2003; Simons, 2009; Flick, 2011). Parent and practitioner

participants were asked if the researcher could observe the children, either at home or in their educational setting, then an informal final consent was obtained from the children themselves. This involved introducing myself and in developmentally appropriate terms explaining the reasons for my presence. The absence of any negative reaction was interpreted as passive consent for the observation. Children's verbal and non-verbal behaviour was monitored during observation itself to ensure that there was no adverse impact on their normal routines, activities and interactions.

This process presented one particular dilemma relating to the involvement of other children in the setting, not those directly under scrutiny. While observations were not targeted to involve other children, due to the nature of activities any other children inevitably would be seen interacting with the target child. It was felt appropriate, therefore, to obtain consent from parents of these other children also. An opting-out possibility was felt to be sufficient for this. In the end no parents raised concerns or asked for their children to be withdrawn from the observed sessions.

While potential harm for research participants was judged to be relatively low in all data-collection methods, it was nevertheless essential to ensure that their engagement was not perceived as a negative or aggravating experience, especially when some issues being raised might themselves be of a negative kind or reawaken hurt feelings. Therefore, interviews were conducted in participants' everyday, natural contexts: their office, the setting where they worked or in their home (Drever, 1997). The timings of interviews and observations were negotiated; the surveys were completed at respondents' convenience.

Participants' cultural and socio-economical backgrounds were addressed with sensitivity by designing the surveys in simple, accessible language and adjusting the tone of conversations at interviews to the contexts in which they were carried out. The

researcher gave participants opportunity to express a range of views and concerns, as suggested by Clough and Nutbrown (2012), without losing the focus and the purpose of data collection. In practice this meant allowing participants to tell their own stories, but at the same time applying careful reminders to prevent only the sharing of complaints.

All the interviews were voice-recorded, with permission, and the recordings transcribed. Transcriptions were shared with interviewees for further comment and approval. As well as confirming to interviewees the value of their contributions and making data collection more democratic (Simons, 2009), this process was also felt to increase credibility and trustworthiness (Aubrey *et al*, 2000, Simons, 2009, Robson, 2011) by giving participants opportunity to check, amend or extend the narrative data they had given.

Once a research project is completed, findings need to be shared with those who took part or facilitated the investigation. Information provided to participants explained this intention. On completion of the thesis, therefore, a shorter and simpler version of findings will be shared with local-authority departments, settings and individual participants and if required, also disseminated in oral form.

4.8 Role of the researcher

Parallel to the above methodological and moral requirements, researchers have another responsibility, simply that of being a researcher (Aubrey *et al*, 2000). Indeed, Rubin and Rubin (2003) perceived the researcher in real-life, interpretive enquiries to be one of the most important instruments in the investigation – personal interests and motivations inevitably influence discovery and understanding. The researcher's

prejudices may also be brought into the research process (Aubrey *et al*, 2000). My own academic interest and motivation to engage with this enquiry emerged from my previous pedagogical experiences. This factor indeed appeared both to benefit the study and to threaten its trustworthiness.

In terms of benefit, my experiences helped when negotiating empirical access to data collection and, more personally, access to participants' views and perspectives. It helped too in understanding how participants' attitudes towards childhood, disability, upbringing and early education might associate with particular historical and cultural times, as explained by Aubrey *et al*, (2000) and Patton (2002), and that their voices might not therefore be in harmony with my own perspectives, which were a product of different, cultural and temporal circumstances (Sikes, 2004).

In order to address possible adverse implications, a reflexive approach, as recommended by Aubrey *et al*. (2000), was adopted throughout. During data collection and interpretation in particular, the researcher had to keep in mind that she was not an 'innocent bystander in data-making' (Richards, 2009, p21). Specific strategies involved piloting of research methods, data-checks and the relating of ideas to perspectives in the literature, strengthening open-mindedness about the multiple realities of participants and the various contexts in which early support for the children took place.

In addition, continuous involvement and communication with the participants helped immersion into certain dimensions of their professional and personal lives and consequently led to the researcher gaining a kind of temporary membership in those social contexts which were the focus of the study. This seemed to increase personal sensitivity to their views, practices and experiences in ways described by Angrosino (2008) and enabled synchronization of my own understanding with theirs.

Finally, when interviews and observations were completed, debriefing processes helped to decrease further any potential difficulties with bias. Indeed, some research participants indicated favourably that contributing to the research had given them opportunity to reflect on their own roles and experiences in a different light. Such comments reinforced the collaborative nature of enquiry, in which the researcher's dual responsibility for the research participants and for the investigation itself is a continuous and interweaving process.

4.9 Conclusion

This chapter has provided an overview of the rationale and process of the investigative framework and the corresponding methodology and ethical contemplations developed to explore the research issue as a whole. While these considerations have been addressed separately and sequentially in this chapter, in practice deliberation of strategies took place during planning and implementation in an integrated fashion. The next chapter begins the report on findings of the data-collection process.

CHAPTER 5: SURVEY OF PARENTS

5.1 Introduction

As explained in Chapter 4, data gathering and interpretation in this study were carried out in a sequential fashion. This chapter examines the first dataset in this process, obtained from a survey of parents.

5.2 Aims

The parental survey had two aims. First, by starting with scrutiny of opinions and feelings, a preliminary picture was canvassed (Muijs, 2003), creating basic understanding of specific dimensions of early development and learning of these children, as perceived by the most immediate stakeholders of their upbringing, their parents.

The second aim was more pragmatic. Conducting the parental survey helped to determine the sample for further data-collection methods, in particular, the interviews with the selected parents and practitioners, and the observations of children. With these aims, the parental survey contributed to some degree to the process of answering all the research questions.

5.3 Methods

5.3.1 Respondents

Identification of eligible families for the survey took place through the three local-authority support services. Each of the heads of services showed interest and willingness to establish contact with managers of early-years provisions and other stakeholders so that the questionnaire could be distributed to families of pre-school children with cerebral palsy. The majority of parents were therefore contacted through the early-years settings and provisions which their children attended. A few others received the questionnaire from the local authority's Children with Disabilities Services, using the voluntary disability register described earlier.

5.3.2 Questionnaire

As the size of the sample was relatively small, a paper-based rather than electronic questionnaire was designed and distributed (Appendix B). Its closed questions were clustered into broad categories: demographic information about respondents (Q1, 3 and 6) and their child (Q4 and 5); questions about contextual arrangements for their child's care, early-years education and support (Q7 and 8); a section exploring opinions about processes and strategies to enhance their child's development and learning (Q9, 10 and 11); and finally, questions asking respondents to indicate their priorities for their child's development (Q12). Most questions produced quantitative data, but there were two sections where parents were invited to explain opinions and provide further comments if they wished.

5.3.3 Procedure

Once consent was obtained from the heads of the local-authority teams, as well as from managers and headteachers of early-years settings which the relevant children attended, the questionnaire was distributed to parents, together with information about the research and a request that they take part. This distribution took place between September 2011 and March 2012.

5.3.4 Data analysis

Data analysis was in two forms. Processing of quantitative data using SPSS© software focused on revealing indicative statistical tendencies, rather than predictive correlations for a more extended population. Qualitative data was used to identify issues related to each theme of the questionnaire. The four constituent elements of the PPCT bio-ecological model were used to inform the analysis.

5.4 Results

5.4.1 Sources

Altogether 72 questionnaires were distributed, producing a 69% response rate and receipt of 50 completed questionnaires. Table 5.1 provides an overview of the settings through which these completed questionnaire were distributed to parents.

Source	Frequency	%
Special school	4	8.0
Conductive education	29	58.0
Children centre	1	2.0
Specialist Early Years Service (SEYS)	9	18.0
Primary schools	4	8.0
Disability register	3	6.0
Total	50	100.0

Table 5.1: Sources of responses to parents' questionnaire

More than half the questionnaires were returned by parents reached through conductive education. This provision was not located within the geographical boundaries of the local authority and attracted children from a wide area. However, it was a regularly 'bought-in' specialist educational service for this local authority, complementing its own provision. The majority of parental respondents from this source had little or no connection with the local authority being researched, but in terms of research aims, strategy and ethics, there was no reason to exclude them from the survey just because their home lay outside the local-authority area. Secondly, their contribution to the survey extended the survey's scope and enriched data for interrogation.

The second most frequent set, nearly one fifth of returned questionnaires, came from parents linked to the authority's Specialist Early Years Service (SEYS). This service provided input at children's own homes and in other settings as a form of 'outreach', and therefore had extensive contact with both families and settings. Completed questionnaires were also received from parents with children attending nursery classes and foundation units of special and primary schools (four each), from a children centre (one), and from three parents who received the questionnaire from the local-authority department which maintained the disability register. Questionnaires were also sent to parents through child minders and a specialist voluntary nursery, but no returns were obtained from these sources.

5.4.2 Respondents

All returned questionnaires were eligible for inclusion in the study. The vast majority of respondents, 45 out of 50, were mothers. Two fathers, two grandmothers and one legal carer also completed the questionnaire. All but the two father respondents were female. Nineteen respondents identified the disabled child as the only child within the family; the same number was bringing up two children. Seven families had three children, and four families had four. Eighty per cent of parent respondents declared themselves as being of white British ethnicity, others came from six other backgrounds.

5.4.3 Represented children

Demographic information was also gathered about the children of the parents completing the survey. Just over a quarter were children aged two years. A fifth of parents were referring to one-year-old children, a fifth to five-year-olds, with representation of three- and four-year-olds slightly less than this. Only two children were aged below 12 months.

Nearly two thirds of the children described by parents were male; just over one third were female. Both father and both grandmother respondents portrayed male children, and the legal carer was parenting a female child. Male children represented in the survey tended to be younger children. For instance, 22.6% of boys were aged one year, compared with only 15.8% of girls. On the other hand 16.1% of boys were aged five, compared with 26.3% of girls.

5.4.4 Early-years provision

Parents were asked to indicate the provisions or services attended by their children at the time of completing the questionnaire. Twenty-one out of the 50 respondents indicated only one kind of provision; 18 indicated two kinds; the remaining 11 parents indicated three or more (Table 5.2).

No. of provisions attended	Frequency	%
1	21	42.0
2	18	36.0
3	6	12.0
4	3	6.0
5	2	4.0
Total	50	100.0

Table 5.2: Parents' identification of the number of provisions attended by their children

In total, the 50 children represented in the survey attended or participated in 20 different kinds of provision (Table 5.3):

Provisions	Frequency	%
Private day-care nursery	12	12.4
Nursery unit in primary school	2	2.1
Reception class in mainstream school	5	5.2
Nursery unit in special school	7	7.2
Reception class in special school	6	6.2
Day-care nursery in children centre	2	2.1
Short breaks	3	3.1
Child minder	3	3.1
Portage work	11	11.3
Local play-group	10	10.3
Other: Conductive education	17	17.5
Other: Special school	3	3.1
Other: Swimming	3	3.1
Other: Respite care	2	2.1
Other: Physiotherapy	4	4.1
Other: Care by relative	2	2.1
Other: Children centre	1	1.0
Other: Early support	2	2.1
Other: Teacher for visually impaired	1	1.0
Other: Speech & language therapy	1	1.0
Total	97	100.0

Table 5.3: Early-years provision for children of respondents to parents' questionnaire

The most common form was conductive education (17.5%), reflecting the fact that this provision was the source of more than half of the returned questionnaires. Responses also indicated frequent use of private day-care nurseries (12.4%), regular involvement in early Portage work (11.3%), and participation in local playgroup activities (10.3%).

This question also gave parents the option to indicate any 'other' provision their child attended or from which they received input. Nine 'other' provisions were identified, including physiotherapy, speech and language therapy and respite care.

Matching the age of children against the number of provisions highlighted several tendencies (Table 5.4). Younger children often attended or received input from three, four or even five services, but this number showed steady decline with increasing age. For four-year-old children, connection with two services was typical, reducing usually to one by the age of five.

Child's age	Number of provisions attended					Total
	One	Two	Three	Four	Five	
Below 12 months	0	0	0	1	1	2
1 year	3	4	1	1	1	10
2 years	6	2	4	1	0	13
3 years	2	4	1	0	0	7
4 years	3	5	0	0	0	8
5 years	7	3	0	0	0	10
Total	21	18	6	3	2	50

Table 5.4: Age of children and number of provisions attended.

Portage work was more frequently provided for children aged one and two (56%) than for children of other ages, as might be expected. Local playgroups were most commonly used for two-year-olds (40%), similarly private nurseries (50%), although these were also used by one-year-old (25%) and four-year-old children (25%).

Conductive education was used by all ages, but in particular by families with children aged one (23.5%).

5.4.5 Provision for development and learning

Parents were also asked to identify what they felt was the most useful provision for their child's learning and development. Data showed a wide range of choices, with formal, group-based provision – conductive education, reception class in special school and private day-care nursery – being marginally more popular than services provided on an individual basis, such as Portage work or child minding. Nine parents identified two provisions as being 'most useful,' rather than one. When these responses were added to the data, conductive education gained most in popularity, representing nearly one fifth of provisions identified.

When children's age and all the most useful provisions were cross-tabulated, ratings mirrored the nature of input the children actually received. For instance, private day-care nursery was most commonly identified as 'most useful' for children aged one and two, reception classes in a mainstream or special school for those aged four and five.

Parents were also invited to provide some rationale for their choice. In response, they gave a broad variety of reasons. These included furtherance of particular areas of the child's development, the nature and processes of the provision, the attitude and experience of staff, or benefits for themselves as parents.

Private day-care nurseries were predominantly associated in these qualitative comments with development of early social skills. For example: 'It helps my son become more independent and gets him to interact with other children his own age' (mother of two-year-old boy); 'Private nursery [is useful] for very early social skills'

(mother of two-year-old boy). With older children, nurseries located in special schools were described as focusing on children's specific needs: 'They concentrate on my daughter's special needs. Smaller group of children with virtually one-on-one care from the teachers' (mother of four-year-old girl); as providing continuity: 'Special school nursery [is useful] for ongoing education' (mother of four-year-old boy); and for teaching independence, as cited by the mother of a girl aged five: 'It was her first step towards independence as she was a very clingy child. The setting was perfect for her physical needs and much more.' Similarly, the father of a four-year-old boy highlighted the usefulness of the range of experiences and interactions provided by special nursery: 'The wide range and variety of activities and classes he takes part in has allowed him to experience different things that he both enjoys and has made a positive difference to him.'

On the other hand, the mother of a four-year-old girl in a reception class emphasized more the social and academic benefits of being together with children from the community: 'Reception class in mainstream school as she is no different from the other children academically and she is on par with her peers in all areas of the curriculum.' For the mother of a three-year-old boy, mainstream nursery provided appropriate expectations in particular areas of learning: 'E. needs to mix with other children in school. They show E. that he is not the same as them (i.e. not walking), but I feel it encourages him to try to improve his mobility and speech.'

Conductive education, which scored highly amongst parents of children of all ages, was linked to opportunities for physical activity and independence: 'Conductive education offers my child physical opportunities which are challenging but achievable' (mother of four-year-old boy); and to development of independence: 'Conductive education because it teaches him how to be more independent' (mother of five-year-old boy). The mother of a boy aged under 12 months wrote: 'Conductive education

due to variety of exercises suggested and concentrating not only on what he can but also he COULD do if was a normal child, while physio only concentrate on sitting and rolling.’ Conductive education was also selected for its benefits for parents themselves, as cited by mother of two-year-old boy: ‘Conductive education has proved the most useful for “teaching” both W. and us.’

Portage work, used by families with younger children aged one and two, was associated primarily with processes of overall development: ‘Portage is brilliant for focusing on specific targets and for her to be brought appropriate toys. I like the way it works on physical/communication/cognitive development’ (mother of two-year-old girl); ‘Portage has been extremely helpful with B.’s development in all areas’ (mother of one-year-old boy). Another parent described more detailed benefits: ‘They are very knowledgeable about activities and development and have many toys, facilities, etc. They work to IEPs [Individual Education Plans] and alongside other professional therapists attached to child. They give good ideas to use at home’ (mother of one-year-old boy).

Short breaks also attracted comments. These helped the mother of a four-year-old boy to meet needs of the wider family: ‘It lets me do the shopping, clean, many other duties, spending time with my son.’ For another, the mother of a boy aged two, it meant having a knowledgeable person to care for her child: ‘His short break is provided by a carer, who has been trained to meet his needs. It is 1-1 care.’

The benefits of having involvement with a combination of services with differing practical focus were also highlighted, for example: ‘Private nursery [is useful] for very early social skills. Special school nursery [is useful] for ongoing education’ (mother of four-year old boy). The benefits of using a child minder were also mentioned by a mother in relation to her two-year-old daughter: ‘It is really beneficial for her to be

around other children and to socialise with children and other adults. Our child minder does everything in Makaton which really helps with her communication’.

Finally, a few parents indicated disappointment with services, rather than describing their benefits. Three out of 50 respondents indicated that they did not regard any services helpful, as the support they received was ‘None’ (mothers of one-year-old, two-year-old and five-year-old boys). A fourth mother, with a boy aged five, stated starkly: ‘Don’t feel I have had much help.’

5.4.6 Characteristics of development and learning

The next cluster of questions focused on parents’ perspectives about some of the characteristics of their child’s development and learning. Parents were asked firstly to score the extent to which, in their opinion, these were influenced by their condition, cerebral palsy. Seventeen aspects of development were listed for evaluation, covering physical development, communication, socialization and other aspects, with an option to add ‘other’ items.

As shown in Table 5.5, most children were perceived by parents as being severely affected by their cerebral palsy. Out of 838 responses across all questions, 312 responses (37%) indicated ‘Affected a great deal’. For 11 out of the 17 areas of development, this was the most frequent response. Looking only at this highest category, the area which stood out was ‘Moving around’ (36 responses). Then came a group of five: Speech (27 responses), ‘Dressing’ (also 27), ‘Communication’ (26), ‘Using hands’ (24) and ‘Toileting’ (24). Least affected, according to parents, were ‘Socialising’ (9), ‘Confidence’ (8) and ‘General health’ (8).

When the responses which indicated that areas of development were affected ‘A great deal’ or ‘To some extent’ were combined, the picture was generally similar. ‘Moving around’ maintained its prominence with 48 responses. ‘Dressing’ attracted 38 responses, and a group of three: ‘Using hands’, ‘Playing with others’ and ‘Communication’ each had 36. Three other skills associated with communication: ‘Playing with objects’, ‘Speech’ and ‘Making themselves understood’, each had 33 responses. At the other end of the rankings, ‘Confidence’ (20) and ‘General health’ (18) retained their relatively low scores.

No.	Skills affected	Affected a great deal	Affected to some extent	Affected a little	Not affected at all	Not sure	No response
1.	Moving around	36	12	2	0	0	0
2.	Using hands	24	12	9	4	1	0
3.	Playing with objects	21	12	13	4	0	0
4.	Playing with others	18	18	9	3	2	0
5.	Communication	25	11	4	8	2	0
6.	Speech	27	6	6	7	3	1
7.	Making themselves understood	19	14	7	6	2	2
8.	Understanding	11	14	9	14	2	0
9.	Paying attention	15	13	9	10	2	1
10.	Socialising	9	18	10	12	0	1
11.	Confidence	8	12	14	9	6	1
12.	Motivation to do things	10	15	10	12	0	3
13.	Eating and drinking	19	6	13	11	1	0
14.	Toileting	24	7	6	4	8	1
15.	Dressing	27	11	6	2	4	0
16.	Sleeping	11	13	8	15	1	2
17.	Generic Health	8	10	10	18	2	2

Table 5.5: Overview of perceptions of respondents to parents' questionnaire of the extent to which areas of skills were affected by their child's cerebral palsy

Combining items under more general themes allowed scrutiny of parents' perceptions about how cerebral palsy was affecting overall categories of development in their children. So the three skills associated with motor performance: 'Moving around', 'Using hands' and 'Playing with objects', averaged a score of 39 responses each in the categories of 'Affected a great deal' and 'Affected to some extent'. Skills of communication: 'Communication', 'Speech' and 'Making themselves understood' had a lower average of 34 such responses each. Skills relating to social development: 'Playing with others' and 'Socialising' scored lower again with an average of 31.5, as did those associated with self-care: 'Dressing', 'Toileting' and 'Eating and drinking', with an average of 31. The impact of cerebral palsy on processes of cognitive development: 'Paying attention' and 'Understanding' had a even lower average of 27. Two aspects of wellbeing: 'Sleeping' and 'General health' had an average of 23; skills relating to emotional development: 'Confidence' and 'Motivation' had the lowest average of all, 22.5.

The next scrutiny of parents' opinions involved them choosing three aspects of development which, in their opinion, received the most attention from practitioners working with their child in the settings they had identified and then ranking them to reflect the extent of attention each received. In their first choice (Table 5.6) 'Physical skills' (e.g. sitting, standing) easily outscored other areas – 25 parents chose this. Eight chose 'Mobility' in this category.

	Frequency	%
Physical skills	25	50.0
Hand skills	2	4.0
Communication	2	4.0
Mobility	8	16.0
Cognitive skills	3	6.0
Social skills	1	2.0
Self-care skills	1	2.0
Not ranked or not stated	8	16.0
Total	50	100.0

Table 5.6: Parents' identification of aspects of their child's development receiving most attention from practitioners: first choice.

Parents' second choice was more varied (Table 5.7): 'Physical skills', 'Hand skills', 'Communication', and 'Mobility' were each identified by around one fifth of respondents.

	Frequency	%
Physical skills	9	18.0
Hand skills	10	20.0
Communication	9	18.0
Behaviour	1	2.0
Mobility	8	16.0
Cognitive skills	4	8.0
Not ranked or not stated	9	18.0
Total	50	100.0

Table 5.7: Parents' identification of aspects of their child's development receiving most attention from practitioners: second choice.

The third choice also showed variation (Table 5.8). With 'Physical skills' already covered by more than two thirds of respondents' first and second choices, the aspects of development selected most frequently as a third-ranked choice were 'Hand skills', 'Communication', 'Mobility' and 'Cognitive skills', each with between seven and nine responses.

	Frequency	%
Physical skills	3	6.0
Hand skills	9	18.0
Communication	9	18.0
Mobility	8	16.0
Cognitive skills	7	14.0
Social skills	4	8.0
Self-care skills	1	2.0
Not ranked or not stated	9	18.0
Total	50	100.0

Table 5.8: Parents' identification of aspects of their child's development receiving most attention from practitioners: third choice.

In addition to this data, six parent respondents made choices but did not rank them. Table 5.9 puts these with the ranked responses and shows all choices made by parents, unranked. This overview shows that more than a quarter of parents identified

‘Physical skills’ as receiving most attention in their child’s provision, followed by ‘Mobility’ (18.7%), ‘Hand skills’ (14.7%), ‘Communication’ (14%) and ‘Cognitive skills’ (11.3%). At the other end of the scale, ‘Social skills’ scored low (4%), while ‘Self-care skills’ (2%) and ‘Behaviour’ (0.7%) hardly scored at all.

Aspects of development	Frequency	%
Physical skills	41	27.3
Hand skills	22	14.7
Communication	21	14.0
Behaviour	1	0.7
Mobility	28	18.7
Cognitive skills	17	11.3
Social skills	6	4.0
Self-care skills	3	2.0
Not stated	11	7.3
Total	150	100.0

Table 5.9: Parents’ identification of aspects of their child’s development receiving attention from practitioners: all choices

Parents were also invited to identify three areas of their child’s development in which they would welcome more input from professionals, and again to rank these according to importance. About one-fifth of parent respondents did not answer this question. Amongst others, ‘Communication’ was the area most frequently identified as the first choice (8 responses), followed closely by ‘Physical skills’ (7). Other aspects were also represented in parents’ first choices, albeit with lower frequencies. For the second-place choice, ‘Communication’ was again the favourite, although this time more marginally so (7 responses), with ‘Social skills’ next (6) and ‘Mobility’ (5) after that. For the final, third choice of areas where more input was wanted, ‘Self-care skills’ (7 responses) was the most frequently identified, followed by ‘Social skills’ (6) and ‘Hand skills’ (5). Nearly half of respondents did not provide a third choice.

Again, as with the question about areas of development receiving attention, all three choices were combined in unranked form – see Table 5.10. When presented in this

way, 'Communication' was again the most popular choice for more input, with 18 out of 89 responses (12%). 'Social skills' came next with 16 scores (10.7%), and 'Physical skills' third with 12 (8%).

Aspects of development	Frequency	%
Physical skills	12	8.0
Hand skills	9	6.0
Communication	18	12.0
Behaviour	7	4.7
Mobility	8	5.3
Cognitive skills	9	6.0
Social skills	16	10.7
Self-care skills	9	6.0
Other: physiotherapy	1	.7
No response	61	40.7
Total	150	100.0

Table: 5.10: Parents' identification of aspects of their child's development needing more attention: all choices

5.4.7 Priorities

Accompanying the question about areas for greater professional input, parents were asked also to indicate their own priorities for their child. For this they were presented with 14 skills associated with the main areas of child development and learning and asked to indicate the extent to which they themselves regarded these areas as important. While all 50 respondents provided a response, there was reluctance amongst some to discriminate between items. Seven ticked 'Very important' for all items, and two selected all but one as 'Very important', reducing differentiation in the data obtained. When only the highest response: 'Very important', was considered, three priorities stood out strongly: 'Moving about' (41 responses), and two areas of communication: 'Communicating with other children' (37) and 'Communicating with adults' (36).

However, when the two highest responses: 'Very important' and 'Important' were combined, a rather different picture emerged (Table 5.11). All three of these areas were grouped closely together: 'Moving about' with 49 responses, 'Communicating with adults' with 48, and 'Communicating with children' with 47. At the other end of this spectrum, the least strong developmental processes in the list of parental priorities were 'Influencing behaviour' (23 rated this as 'Very important'; 39 as 'Very Important' or 'Important'), and 'Dealing with medical demands' (22 rated this 'Very important'; 32 as 'Very Important' or 'Important').

No.	Strategy	Very important	Important	Not very important	Not important at all	Not sure	No response
1.	Playing individually	15	26	7	2	0	0
2.	Playing with other children	31	17	1	1	0	0
3.	Using hands at table-based activities	31	16	1	1	0	1
4.	Moving about	41	8	0	0	0	1
5.	Communicating with other children	37	10	1	2	0	0
6.	Communicating with adults	36	12	0	2	0	0
7.	Eating and drinking independently	33	9	3	4	1	0
8.	Dressing	20	21	5	2	1	1
9.	Toileting	25	17	4	2	1	1
10.	Carrying out special tasks prescribed by therapists	31	14	3	0	1	1
11.	Using special equipment provided by therapists	27	17	3	0	1	2
12.	Encouraging general participation in activities	27	17	2	2	0	2
13.	Influencing behaviour	23	16	6	1	2	2
14.	Dealing with medical demands	22	10	7	5	4	2

Table 5.11: Overview of parents' identification of priorities for their child's development and learning

Qualitative comments contributed to both the last two items – areas for greater input and parents' own priorities for development and learning, although some respondents

did not make any substantial distinction between the two. Communication, for instance, stood out in both respects: 'I think more time could be spent on developing speech and communication skills. Should also be shared with parents' (mother of four-year-old girl in a private nursery); 'He needs to be able to communicate. I would like him to speak, I think it is important, so that he doesn't get very frustrated and so that I can see his progress. Therefore I think he needs speech therapy' (mother of 2-year-old boy receiving Portage). The mother of a two-year-old girl attending a child minder, playgroup and Portage simply pointed out that: 'Speech and language skills and eating skills are one of the main priorities.'

Physical skills and mobility were also frequently cited. The mother of a one-year-old girl receiving Portage suggested a focus on a combination of such skills: 'Mobility, moving in and out of positions, weight bearing on legs and cruising', as well as on developing the concentration to perform finer tasks: 'Jigsaws, building blocks'. However, more detailed comment from the mother of a two-year-old boy receiving only occasional provision of short breaks expressed disappointment at the lack of input her son received in relation to his physical development:

I think that children with profound mobility problems should receive more physio throughout their life, in school and help for carers at home to do and be helped to do regular routines as it is essential for physical well being of the child's limbs and bones, without it everyday things become more hard and painful such as helping to sit and facilitate arms, hands and legs when dressing. I could go on forever about what our children need, but then actually receiving it is another story!!

Concern with children's emotional development was also evident. For example, the mother of a four-year-old boy attending a nursery class in a special school wanted her child 'to be happy and feel secure in the learning environment'. The mother of five-year-old girl attending mainstream reception class focused on the avoidance of failure:

‘Allow the child to develop in their own time like any other children. Pushing too much undermines their confidence.’

Social experience was also prioritized in some comments: ‘He needs to be encouraged to do well but he needs to understand that he cannot always do what he wants as he lives by the same rules as others’ (mother of 3-year-old boy attending mainstream nursery and a child minder). Other respondents expressed views on the contexts in which their child’s social development could take place:

Although Nursery unit at a special school is wonderful, I would like my daughter to still be with mainstream children too. She learns a lot from this. However mainstream school should come to her nursery so that she can be as independent as possible, e.g. toilets, swings are adapted so she can do her very best (mother of five-year-old girl attending reception class in a special school).

The mother of a three-year-old boy attending playgroup wrote similarly: ‘[It] gets him interacting with other children of his own age’. However, there were parents who thought it was important for their child to have experience with other disabled children. For instance, the mother of a two-year-old boy attending a combination of private nursery, Portage work and local playgroup stated that: ‘[It is important that] my son interacts with other children with similar needs.’

Interestingly, only one comment related to priorities in respect of cognitive development. However, the comment, from the mother of a three-year-old girl attending a nursery unit in a special school, suggested that the child’s difficulty was not with cognitive, but with other areas of development: ‘Simplify activities physically, not intellectually.’

5.4.8 Strategies

The questionnaire also asked parents about strategies employed by practitioners when helping their child's development and learning. It presented them with a list of 16 such strategies and asked them to indicate the degree of their importance. Questionnaire items were related to environmental change (for example, 'Changing the environment for easy access'); psychological factors (for instance, 'Positive reinforcement', 'Having consistently high expectations'; 'Building confidence'), and pedagogy (for instance, 'Simplifying activities'; Letting the child learn by trial and error'), and included the option of 'Other'.

The process of evaluating such strategies – as it had been when choosing 'priorities' – seemed difficult for some parents. Again, seven respondents simply graded all those listed as 'Very important'; two graded only one of the strategies as less than this. Nearly all strategies received an overall grading indicating strong importance; only four of the 16 showed some reasonable variation: 'Letting the child learn by trial and error'; 'Letting the child choose whether or not to participate'; 'Telling the child what to do and how', and 'Having consistently high expectations'. Only one parent provided an entry under 'Other' – the response was 'fun'.

When responses to all items were compared (Table 5.12), the strategy of 'Giving positive reinforcement' was the most important of all, with 41 out of 49 respondents regarding it as 'Very important' and all but three perceiving it as 'Very important' or 'Important'. Second in popularity was 'Providing more time', with 38 out of 49 regarding it as 'Very important' and all but three perceiving it as either 'Very important' or 'Important'. 'Letting the child learn by trial and error' was also among the popular strategies – 19 respondents regarded it this as 'Very important' and 24 parents as 'Important', as was 'Letting the child choose whether or not to participate' (Very

important: 19; 'Important': 21) and 'Telling the child what to do and how' ('Very important': 20; 'Important': 22). The strategy regarded as least important was 'Having consistently high expectations' – nearly half of respondents (22 out of 49) gave it a lower grade response than 'Very important' or 'Important'.

No.	Strategy	Very important	Important	Not very important	Not important at all	Not sure	No response
1.	Changing the environment for easy access	28	14	4	1	2	1
2.	Adaptation of toys, tools, equipment, etc.	30	9	7	1	2	1
3.	Providing more time	38	8	2	0	1	1
4.	Simplifying activities	26	17	4	0	2	1
5.	Providing specific activities	30	14	1	0	2	3
6.	Letting the child learn by trial and error	19	24	5	0	1	1
7.	Letting the child choose whether or not to participate	19	21	6	1	2	1
8.	Providing continuous one-to-one support	31	13	4	0	1	1
9.	Increasing motivation	34	12	3	0	0	1
10.	Building confidence	35	10	2	1	0	2
11.	Providing repetitive opportunities for practice	35	11	2	1	0	1
12.	Giving continuous positive reinforcement	41	5	2	1	0	1
13.	Telling the child what to do and how	20	22	3	2	2	1
14.	Providing technology to enhance independence	27	12	6	3	1	1
15.	Having consistently high expectations	16	12	14	4	3	1

Table 5.12: Overview of identification by respondents to parents' questionnaire of the importance of strategies for supporting their child's development

Parents were also asked to identify three strategies from the list which they regarded as the most important for the development and learning of their child. When all choices were combined, 'Providing continuous one-to-one support' was the most popular (21 responses), followed by 'Providing more time' and 'Giving continuous positive reinforcement' (both 14).

When cross-tabulated against the age of children, many strategies, including 'Adaptation of toys, tools, equipment, etc.' and the overall favourite, 'Providing continuous one-to-one support', maintained roughly the same popularity at all ages. Amid small numbers, 'Providing more time' lessened in popularity as the child's age increased, whereas 'Changing the environment for easy access' increased in importance as children reached five, perhaps as they started to make use of more complex surroundings, including school. 'Providing repetitive opportunities for practice' was chosen only for children aged one and two; 'Letting the child learn by trial and error' only for children aged two years and above. 'Having consistently high expectations' was selected only for children aged between two and four; 'Increasing motivation' only for children of two years and below.

Similarly, there were no large differences in strategies chosen as most important in relation to the child's gender. More popular for boys were 'Adaptation of toys, tools, equipment, etc.' and 'Providing repetitive opportunities for practice'. More popular for girls were 'Changing the environment for easy access'; 'Providing more time'; and both the least directive strategy: 'Letting the child learn by trial and error' and the most directive: 'Telling the child what to do and when'.

5.4.9 Willingness to be interviewed

At the end of the questionnaire, parents were asked if they would be willing to take part in an interview if requested. They indicated this willingness by providing contact details. Five parents who completed the questionnaire through the local-authority department holding the register did not receive this question, as the service requested that it be left out of the questionnaire. Of those asked, 23 out of 45 parents agreed to be interviewed if needed.

5.5 Discussion

Parents represent the most immediate and important microsystem of a child's life, the family. The parents in this survey could not be said to be illustrative of all families of children with cerebral palsy, or to represent all kinds of home context in which these children grow up. However, in terms of ethnic diversity, the sample was broadly in line with demographic, national-census data relating to the chosen local authority (Office for National Statistics, 2013). A large majority of respondents, 90%, were mothers, 10% were fathers, echoing what Read (2000) and Pelchat and Lefebvre (2004) highlighted as a disproportional distribution of parenting tasks amongst mothers and fathers of disabled children.

In spite of ongoing national efforts to strengthen and integrate provision for young children and their families as highlighted in the literature review, survey respondents identified 20 different types of early-years contexts with which they were engaged, mirroring a patchwork nature of early-years services in general (Bertman and Pascal, 2002) and of support for young disabled children in particular (Wolfendale and Robinson, 2006). An absence of integrated early intervention meant many had to

engage with separate mainstream and specialist provisions, in some cases up to five different kinds.

Regardless of their child's age and ethnic background, most parents perceived their child's early learning and development as being severely affected by cerebral palsy. Analysis suggested that their predominant concern was for physical development, including mobility, hand co-ordination and communication, matching the main areas usually affected by this condition (Cogher *et al*, 1992; Fox, 2003; Hinchcliffe, 2007; Farrell, 2008) and reflecting a perspective focused on children's primary, biological difficulties (Vygotsky, 1993). Such tendencies may reflect how the dominant professional discourse influences parents' construction of understanding about their child's disability, as suggested by Landsman (2005) and Fisher and Goodley (2007).

Closer analysis, however, suggested a more complex parental image, one related to development rather than difficulties, perhaps based on sustained hands-on parenting experience. While primary aspects such as communication and physical skills were prominent in their opinions of benefits of provision and in their priorities for future development, other aspects of development, such as social and self-help skills, also appeared on parents' 'wish-list'. Qualitative data also indicated that parents appreciated provisions which encouraged their child's social engagement and where there were broad-ranging activities with other children. These results suggest parents' recognition of the benefits of and need for wider and different learning opportunities, not just the more limited therapeutically based, compensatory strategies and exercises which stress a more singular aspect of a disabled child's development.

Secondly, parents' apprehension about both their child's physical and their psychological development suggested concern for overall upbringing, rather than for particular aspects of development and learning. Ideas from Bakonyi (1971), Millei

(2011) and Cockerill (2012) about nurturing of all children in their earliest years are relevant here, in particular their suggestion that upbringing which fosters all-round development, rather than emphasis on one or another aspects, is essential.

In relation to preferred practical strategies for early development and learning, responses reflected a balanced outlook. There was a disinclination simply to leave the child to learn, for instance by letting him or her choose whether or not to participate, but also little eagerness to push or direct the child too much, or to be over-didactic in approach. Parents recommended adult facilitation, such as giving one-to-one support, giving more time and especially giving positive reinforcement, but they also wanted children to be allowed to use their own attempts and effort.

This implies a combination of child and adult-led interactions and activities, rather than being either over-didactic or *laissez-faire*. Strategies such as adaptation of toys or environment and use of technology, broadly identified in the literature as important (Finney, 1974; Willis, 2009; Westwood, 2013) were less popular than this more psycho-pedagogical perspective. The combination echoes too Hári's (1997a) balanced assertion in which the role of adults in children's learning includes both sensitivity and confidence in applying goals and expectations and adaptation of social and physical circumstances within which activities take place.

Finally, at a practical level, findings suggested differences between perceptions about difficulties and about which areas of development were felt to receive most attention in the various professional contexts in which the child was involved. Physical skills and areas of communication were prominent in both, but cognitive skills, which had not been marked by parents as being greatly influenced by their child's cerebral palsy, were seen as a prominent area of attention in provision, perhaps reflecting Leach's (2011) concern about over-emphasis in this area in the early-years curriculum. Self-

help on the other hand was hardly identified at all as part of provision, despite being signaled by parents as an aspect of development strongly affected by their child's cerebral palsy.

5.6 Conclusion

Parental outlooks resulting from the questionnaire survey, the first perspectives examined in this study, covered all aspects of the Bronfenbrenner model. Consideration of 'person' focused predominantly on the impact of cerebral palsy on the child. 'Context' addressed the involvement of children and parents with a broad range of childcare, education and specialist provisions, with different roles and benefits allocated to each, as highlighted earlier by Flewitt and Nind (2007). In relation to 'process', parents considered their own roles and the roles of professionals in providing their child with development and learning opportunities. In terms of 'time', there was apprehension for children's future, not just for aspects which at their youngest age were being targeted for professional attention. Scrutiny now moves to a second set of perspectives on such themes, those of practitioners.

CHAPTER 6: PRACTITIONER SURVEY

6.1 Introduction

Parental perspectives are only one set of outlooks on development and learning of children with cerebral palsy. Other microsystems exist outside of the home, namely professional contexts of early-years childcare and education services, children centres, nurseries and schools. The perspectives of practitioners working with these children in such settings were examined in the second set of questionnaires.

6.2 Aims

The underpinning rationale of the practitioners' survey was similar to that of the survey of parents. It aimed to develop a bio-ecologically oriented, generic overview of the views of practitioners involved with the children in their second most important micro-context, their early-years settings and services. Again, this data source contributed to answering all research questions. It also provided opportunity eventually to interrogate data, integrating findings with others emerging from parental questionnaires.

6.3 Methods

6.3.1 Respondents

Relevant early-years services and settings where eligible practitioners worked were identified through the authority's three support services and provided the main platform for distributing the questionnaires. Contact with gatekeepers of these settings was established and a range of staff identified with experience of working with children with cerebral palsy which would enable them to contribute meaningfully to the survey. The sample consisted of staff with various roles and responsibilities in home- and setting-based provisions, including maintained as well as private and voluntary organizations.

6.3.2 Questionnaire

As with the parental survey, the practitioner questionnaire was paper-based (Appendix C). It comprised 15 closed and three open-ended questions, the latter asking respondents to provide detail, elaborate or make additional comments. Questions were clustered into three main groups: firstly, those asking for demographic information about respondents (Q1, Q2); requests for information about their professional backgrounds – roles, type of settings where they worked, highest qualifications, experience and professional development (Q3-Q11); and questions related to perspectives on early development and learning of children with cerebral palsy (Q12-Q17).

6.3.3 Procedure

With permission from gatekeepers, questionnaires were distributed in various settings between November 2011 and May 2012. Completed forms were in most cases then returned by settings; a few were returned by respondents direct to the researcher. Child minders received the questionnaire through the Family Information Service, the manager making them aware of the research through their electronic newsletter. Child minders were asked to contact the researcher directly if they wished to participate – these practitioners received and returned their questionnaires by post.

6.3.4 Data analysis

The deliberate overlap between the parental and practitioner survey meant that the initial data scrutiny could follow the same procedures as already described in Chapter 5. Quantitative data analysis again focused on identifying simple tendencies and cross-tabulations in the data using SPSS© software. Qualitative comments were interrogated according to coded themes and issues.

6.4 Results

It is estimated that the questionnaire went to 186 practitioners working in various early-years provisions responsible for young children's early childcare, education and additional support. Eighty-five completed questionnaires were received in return, all meeting the criteria for inclusion in data analysis. The estimated response rate was, therefore, 45.7%, slightly lower than in the parental survey.

6.4.1 Source

Completed questionnaires were received from seven types of early-years provision. Over one third of questionnaires had been distributed by the Specialist Early Years Service (SEYS), whose practitioners had a dual role – providing home-based input for families with children with special educational needs and disabilities and supporting work in maintained, voluntary and private early-years settings. One fifth of responses came from Foundation-stage units of primary schools and slightly fewer from similar units in special schools, including both nursery and reception classes. Questionnaires were also returned from conductive education, a specialist nursery and child minders.

6.4.2 Practitioners

Eighty out of the 85 practitioner respondents declared a white British background; the other five came from two other ethnic backgrounds, Asian-Indian and 'Other – white'. All but one respondent were female. Respondents used 23 different terms to describe their roles within early-years services. Following some rationalization of this data, 11 categories of these roles were drawn up, shown in Table 6.1.

Roles	Frequency	%
Child minder	5	5.9
Early years practitioner	31	36.5
Early years teacher	19	22.4
Conductor	2	2.4
Higher level teaching assistant	1	1.2
Learning support assistant	19	22.4
Headteacher	1	1.2
Centre manager	2	2.4
Other: SENCo	3	3.5
Other: Head of Service	1	1.2
Other: Volunteer	1	1.2
Total	85	100.0

Table 6.1: Professional role of respondents to practitioners' questionnaire

More than one third of practitioners (36.5%) described themselves as 'early years practitioner', nearly one quarter as 'early years teacher' and as 'learning support assistant' (22.4% each). Other job roles were much less frequent – these included child minder, SENCo, conductor and centre manager, also a head teacher, one higher-level teaching assistant and a volunteer.

Practitioners were then asked to indicate their highest level of professional qualification against nine categories, including 'Other'. Data indicated a broad range of professional and academic credentials, ranging from GSCE to post-graduate, Masters-level certification. The most common qualification was NVQ Level 3 – over one third of respondents had this, followed by 16.5% with an Honours degree and the same number with post-graduate qualifications. Albeit in small numbers, other highest qualifications included NVQ Level 2 and Level 4 qualifications, GSCE, NNEB, teaching certificate and an ordinary degree.

Respondents were also invited to specify the early-years context or contexts in which they worked, choosing from twelve options, including 'Other'. Seventy respondents indicated they worked in one setting only; six listed two settings; and six others indicated three or more settings, including two who worked in six different settings. Those working in multiple contexts were part of the SEYS team. Table 6.2 gives an overview of all the settings which respondents identified, 116 in total.

Findings suggested that the highest number of respondents were involved with children with cerebral palsy in Foundation unit classes of primary schools (22%), followed by nursery units of primary schools (12%) and nurseries in children centres (11%). Less frequently, respondents were working in the independent, private or voluntary sectors, or as child minders or in specialist provisions. As with the parental questionnaire, however, these figures may say as much about the willingness of

practitioners to participate in the survey and the readiness of gatekeepers to facilitate participation, than about the actual number and distribution of practitioners in relevant workplaces.

Settings and services	Frequency	%
Local authority day-care nursery	11	9.5
Nursery attached to primary school	14	12.1
Foundation unit at primary school	26	22.4
Nursery unit in special school	4	3.4
Foundation unit in special school	3	2.6
Independent day-care nursery	8	6.9
Nursery unit in children centre	13	11.2
Child-minding	4	3.4
Work with children at home	11	9.5
Voluntary organization	10	8.6
Private organization	5	4.3
Other: Specialist nursery	5	4.3
Other: Special unit	2	1.7
Total	116	100.0

Table 6.2: Work settings of respondents to practitioners' questionnaire

6.4.3 Experience

Respondents were asked to indicate the extent of their relevant professional experience in three aspects of their work: generally in early-years services; more specifically with children with special educational needs and disabilities, and most specifically of all, with children with motor difficulties such as cerebral palsy. In relation to the first of these, findings indicated extensive practical experience working with children from birth to five. Almost a quarter of respondents had more than 20 years' experience of this kind; one fifth had experience of between six and ten years. For nearly another one fifth, however, experience was much more limited, just below two years. When this data was interrogated in relation to the sources of the questionnaires, it became apparent that conductive education and the specialist nursery had the highest percentage of respondents who had worked for more than

20 years with pre-school children. However, the strongest overall profiles were shown by child-minder respondents, all four of whom had more than six years' experience, and the larger number of those working with SEYS, more than 80% of whom had more than six years' experience. Questionnaires submitted from nursery units and reception classes of primary schools had the weakest profile. More than half of respondents from these settings indicated less than five years' experience with this age group, followed by children centres (44.4%) and those working in special schools (38.5%).

A similar tendency emerged when practitioners' experience in the more specific area of special educational needs and disabilities was interrogated, as shown in Table 6.3. Results suggested that over a quarter of practitioners had more than 20 years' experience in this area of early-years practice: one fifth indicated involvement of between six and ten years. However, again, for nearly one fifth experience was limited, below two years.

Extent of experience	Frequency	%
None	1	1.2
0-2 years	15	17.6
3-5 years	14	16.5
6-10 years	17	20.0
11-15 years	13	15.3
16-20 years	3	3.5
20+ years	22	25.9
Total	85	100.0

Table 6.3: Experience working with children with special educational needs and disabilities of respondents to practitioners' questionnaire

When this experience was scrutinized against the sources of the returned questionnaires, a range within each setting was evident from little to substantial experience. Amid small numbers, conductive education and specialist nurseries again showed the highest rate of respondents with experience of over 20 years.

Special schools and SEYS had the highest rate of experience over 11 years. Practitioners working in children centres on the other hand had the highest percentage of respondents with less than two years' experience.

In relation to the extent of particular experience with children with cerebral palsy, a different picture emerged. Well over two thirds of practitioners had less than two years' experience working with these children. Only around 28% indicated between three and ten years' experience; nearly one fifth had extensive experience over 20 years (Table 6.4).

Extent of experience	Frequency	%
None	3	3.5
0-2	34	40.0
3-5	13	15.3
6-10	11	12.9
11-15	6	7.1
16-20	2	2.4
20+	16	18.8
Total	85	100.0

Table 6.4: Experience working with children with cerebral palsy of respondents to practitioners' questionnaire

When analysed against sources of questionnaires, conductive education scored the highest percentage of those with experience of over 20 years in this specific area. On the other hand, more than half of the respondents from specialist nurseries, child minding and Foundation-stage units of primary schools had less than two years' experience. Most variation relating to this area was found in questionnaires returned from SEYS, with more than two thirds of respondents indicating ten years' experience or less, but also a quarter revealing involvement of more than 20 years.

6.4.4 Professional development

This survey also sought to illuminate the extent and nature of short or long award-bearing courses which practitioners had attended, then to evaluate the extent to which they felt these courses helped them to support children with motor difficulties such as cerebral palsy. Results suggested a rather varied picture. Nearly half (44.7%) indicated that they had attended no courses or did not give a response. Almost a quarter (23.5%) indicated more than two courses, others either one or two such courses.

Respondents listed 95 kinds of courses altogether, some giving clear specific titles, others providing general information only. Five respondents simply indicated that they had attended 'many courses', without any specification. Those listed by respondents could be clustered into ten broad categories. Most popular were those on particular types of disabilities (21 instances). Amongst these nearly half related to autism, the rest to six other disabilities, one of which was cerebral palsy, attended by four participants. Also popular were courses on communication, speech and language (17 instances) nearly half of which related to Makaton signing, and health and safety and safeguarding (16 instances). Nine indicated attendance at courses on 'manual handling', courses that would probably have particular relevance to those working with children with mobility difficulties, including those with cerebral palsy.

There were only four instances where practitioners attended courses about 'Curriculum and pedagogy' in relation to the teaching of children with special educational needs, and two of these related to out-of-school activities. None appeared to be concerned with teaching issues related to the EYFS framework, and only the course on 'oligophrenic pedagogy' (the teaching of children with learning difficulties) may have broadly related to the upbringing or education of disabled

children. The respondent who gave this response may have been working temporarily in the UK, and given the terminology used to describe it, may have been referring to a course held in another country.

When information about the number of courses attended was correlated with respondents' experiences of working with children with special educational needs and disabilities, two divergent tendencies were evident. While practitioners with 20 or more years' experience attended the most courses of all the categories, this group also had the highest number of respondents who had not attended any, or who gave no response to the question. These were followed by respondents with 6-10 years' experience: 41% of these practitioners had not attended any courses or did not respond to this particular question. Amongst those with 11-15 years' experience, 61.6% had no attendance or gave no response. The lowest attenders were practitioners with 16-20 years experience – all three of these respondents had either attended no courses or did not give a response.

Once formal and award-bearing courses and training had been clarified, practitioners were asked to share their views about less formal opportunities which may have enhanced their professional understanding and practical skills when working with children with cerebral palsy. Eleven categories of such practical opportunities were provided in the survey, including 'None, I have not had any of the above' and 'Other'. Respondents were asked to select all those which they felt helped them to work more effectively with these children (Table 6.5).

Seven of the 85 respondents ticked all of the nine specified items; three identified 'None'. Most selected between three and seven options. Three ticked 'Other' and provided detail – two of these suggested that their experience with their own disabled

child gave them understanding and skills, the third felt ‘discussion with more experienced colleagues’ had been helpful.

According to results, the item selected by most respondents was ‘My own practical experience with children themselves’ (67), closely followed by ‘Advice given by parents of the child’ (66); ‘Practical guidance from experienced colleagues’ (63); and ‘Advice from the child’s therapists’ (63). Scoring least highly were ‘Visiting other settings where they work with these children’ (22); ‘Guidance from area SENCo’ (24); ‘My own research about cerebral palsy’ (31) and ‘Home visits’ (31).

No.	Description	No. ticked
1.	Practical guidance from experienced colleagues within setting	63
2.	Advice given by parents of the child	66
3.	Advice from the child’s therapists	63
4.	Guidance from the area SENCo	24
5.	Home visits	31
6.	My own practical experience with children themselves	67
7.	Observing others working with the child	59
8.	My own research about cerebral palsy	31
9.	Visiting other settings where they work with these children	22

Table 6.5: Overview of practitioners’ evaluation of informal opportunities for strengthening understanding and skills in relation to working with children with cerebral palsy

Respondents were then asked to indicate which of these informal learning opportunities they found most useful. Those most frequently identified in this way were ‘Practical guidance from experienced colleagues within the setting’ and ‘Advice from the child’s therapist(s)’, with nearly a quarter of responses each. Least frequently chosen were ‘Observing others working with the child’ (3 responses); ‘Visiting other settings where they work with these children’ (2); and ‘My own research about cerebral palsy’ (1).

6.4.5 Professional confidence

Respondents were requested to self-assess the extent of their professional knowledge and understanding of the development and learning needs of children with cerebral palsy and their confidence in meeting their needs. They were asked to score their feelings on an ordinal rating scale of 'Very confident'; 'Confident'; 'Slightly hesitant'; 'Hesitant'; or 'Not sure'. Most respondents felt either 'Confident' (33%) or 'Slightly hesitant' (30%). Only a small number of practitioners considered themselves to be 'Very confident' (9%) or 'Very hesitant' (8%). Five participants were either not sure or did not give a response (Table 6.6).

	Frequency	%
Very confident	9	10.6
Confident	33	38.8
Slightly hesitant	30	35.3
Very hesitant	8	9.4
Not sure	2	2.4
No response	3	3.5
Total	85	100.0

Table 6.6: Practitioners' self assessment of their knowledge and understanding of the development and learning needs of children with cerebral palsy.

When this information was cross-tabulated against respondents' roles, the highest level of confidence, albeit amidst small numbers, was amongst conductors, who all indicated either being 'Very confident' or 'Confident' in this area. Interestingly, the only other respondents claiming to be 'Very confident' were the headteacher respondent and the volunteer, a result which could be an indication of their perceptions of the level of confidence required to fulfill their own role and responsibilities within the setting. On the other hand, least confidence was found amongst early-years teachers (52.6% were either 'Slightly hesitant' and 'Hesitant') and amongst early-years practitioners (51.6%).

Results of cross-tabulation of the extent of confidence and the sources of the returned questionnaires suggested that the highest levels came from conducive education and special schools. Most hesitancy was declared by practitioners working in children centres, primary schools and in the specialist nursery. Respondents' self-assessment of knowledge, understanding and practical skills was also interrogated against their experience. Overall, as one might expect, extent of experience was related to stronger feelings of confidence. Those with experience over 16 years indicated the highest levels (61.3% suggested they felt 'Very confident' or 'Confident'); those with less than two years' experience indicated the lowest levels (35.3% in these categories), with a steady if not wholly regular gradation in between.

6.4.6 Practitioners' priorities

Practitioners were then asked to make judgments about the importance of 14 areas and skills related to young children's development and learning. They were invited to rate these as 'Very important'; 'Important'; 'Not very important'; 'Not important at all' or 'Not sure'. Nine out of 85 practitioners ticked 'Very important' for all items and two respondents provided no answer.

When responses to all items were compared, the most popular areas for development were: 'Playing with other children' (56 graded this as 'Very Important'; 25 as 'Important'); 'Communicating with other children' (56 'Very Important'; 24 'Important'); 'Communicating with adults' (55 'Very Important'; 25 'Important'); and 'Encouraging general participation in activities' (53 'Very Important', 25 'Important'). Least popular, although still strong in overall profile, were: 'Dressing' (17 'Very Important'; 45 'Important'); 'Toileting' (20 'Very Important'; 47 'Important'); and 'Playing individually' (20 'Very Important'; 43 'Important').

Practitioners then needed to select three areas from the list which they felt were the most important for young children with cerebral palsy. Table 6.7 presents all results. These indicate the popularity of areas related to social development: 'Communicating with other children' (39 scores); 'Playing with other children (33); and 'General participation in activities' (33). Least frequently chosen areas were 'Playing individually' (5 scores); 'Using hands at table-based activities' (4); and 'Influencing behaviour' (3). Areas related to self-care also scored low: 'Eating and drinking independently' (5 scores); 'Dressing' and 'Toileting' were not chosen at all.

	Frequency	%
Playing individually	5	2.0
Playing with other children	33	12.9
Using hands at table	4	1.6
Moving about	21	8.2
Communicate with other children	39	15.3
Communicate with adults	21	8.2
Eat & drink independently	5	2.0
Special tasks from therapists	22	8.6
Special equipment from therapists	14	5.5
General participation	33	12.9
Influencing behaviour	3	1.2
Medical demands	27	10.6
No response	28	11.0
Total	255	100.0

Table 6.7: Practitioners' selection of the three most important areas of development for children with cerebral palsy

To extend analysis further, practitioners' choices of the three most important areas of development were cross-tabulated against their experience working with children with cerebral palsy. Among the 37 respondents with less than two years' experience, each having three choices, the most frequently chosen area was 'Communication with other children' (18 chose this), while others selected: 'Playing with other children' (13); 'Encouraging general participation in activities' (12); 'Dealing with medical demands' (12) and 'Carrying out special tasks prescribed by therapists' (11).

For the 13 practitioners with between three and five years' experience in this field, the area selected as most important was 'Playing with other children' (8 chose this), followed by 'Communicating with other children' and 'Communicating with adults' (6 each). For the 11 respondents with between six and ten years' experience, the most popular areas for development were 'Moving about' (5 chose this), then five areas: 'Playing with other children', 'Communicating with other children', 'Carrying out special tasks prescribed by therapists'; 'Encouraging general participation in activities'; and 'Dealing with medical demands' (all chosen by four). Six practitioners had between 11 and 15 years' experience in this field – these had three most frequently chosen areas: 'Playing with other children'; 'Communicating with other children'; and 'Encouraging general participation in activities' (all chosen by two), although two gave no responses to this question. The 16 practitioners with the most experience, of 20 years and over, chose most often: 'Encouraging general participation in activities' (11 chose this) and 'Communicating with other children' (8).

Cross-tabulation between these choices and practitioners' roles was also examined. Due to the extent of data, this was only feasible in relation to three roles: child minders, early-years practitioners and early-years teachers. For child minders, the most frequently chosen areas were 'Communicating with other children' and 'Communicating with adults' (four out of five respondents had these as one of their choices). Early-years practitioners chose most frequently 'Communicating with other children' (13 out of 31 chose this), 'Encouraging general participation in activities' (12) and 'Dealing with medical demands' (11). Within this category, 10.8% of responses did not give a choice. Early-years teachers most often chose 'Carrying out special tasks prescribed by therapists' and 'Encouraging general participation in activities' (nine out of 19 chose these), also 'Playing with other children' and 'Dealing with medical demands' (8). 'No response' made up 10.5% of responses. Learning support assistants chose 'Communicating with other children' (10 out of 19 had this

as one of their choices) and 'Playing with other children' (8 out of 19), however 21.1% of responses did not make a choice.

6.4.7 Strategies

The next cluster of questions corresponded to those presented in the parental questionnaire, examined in the previous chapter. Practitioners were asked to indicate the extent to which, in their view, various practical strategies supported the development and learning of children with motor difficulties. Fifteen strategies were listed, including 'Other'. Out of 85 respondents, four ticked 'Very important' for all strategies and two provided no response to any. Overall, however, practitioners showed more readiness to address this question than parents did when responding to their questionnaire.

When scores to all items were listed, the process of 'Building confidence' was seen to be the most important of all for practitioners, with 75 out of 83 respondents identifying it as 'Very important' and all others as 'Important'. Also popular was 'Changing the environment for easy access', with all responses being 'Very important' (64) or 'Important' (19). 'Increasing motivation' also gained high scores – 60 respondents graded it as 'Very important', 22 as 'Important'.

The strategy which was regarded as the least important was 'Letting the child choose whether or not to participate' – only 19 respondents regarded this as 'Very important', and 30 as 'Important'. Twenty-one regarded it as 'Not very important' and 15 as 'Not important at all'. There were no 'Not sure' answers and all respondents graded the items. Similarly, low degrees of importance were given to 'Providing continuous one-to-one support', with 12 respondents indicating that it was 'Not very important' and nine seeing it as 'Not important at all' or being 'Not sure' or not providing a response.

When these results were interrogated in terms of job roles, the strategy scoring the highest percentage amongst the largest number of respondents – early-years practitioners – was ‘Building confidence’ (20%), followed by ‘Changing environment for easy access’ (15.1%) and ‘Providing more time’ (14%). The second largest group of practitioners – early-years teachers – also most frequently chose ‘Building confidence’ (17.5%), again followed by ‘Changing the environment for easy access’ and ‘Having consistently high expectations’, each attracting 14% of responses.

For learning support assistants the most frequently selected practical strategy was again ‘Building confidence’ (17.5%), this time followed by ‘Giving positive reinforcement’ (12.3%) and ‘Changing environment for easy access’ (10.5%), although three respondents (15.8%) provided no response to this question. Amongst the conductor respondents, four strategies had equal importance: ‘Let the child learn by trial and error’; ‘Increase motivation’; ‘Building confidence’ and ‘Providing repetitive opportunities for practice’, each scoring 16.7%.

‘Building confidence’ was again the favourite for child minders (20%), with the other preferences being ‘Providing more time’, ‘Simplifying activities’, ‘Providing continuous one-to-one support’ and ‘Giving continuous positive reinforcement’ (13.3% for each strategy). Both centre managers identified ‘Adaptation of toys, tools, equipment, etc.’ as the most important strategy. For the headteacher it was ‘Providing specific activities’, while the only higher-level teaching assistant chose ‘Changing the environment for easy access’, ‘Providing more time’ and ‘Building confidence’ as equal favourites.

Cross-tabulation was also used to explore the relationship between practitioners’ experience and their preferred strategies. Amongst small numbers practitioners who had no experience of working with children with cerebral palsy chose ‘Adaptation of

toys, tools, equipment, etc' (a third chose this) and 'Changing environment for easy access' and 'Providing technology to enhance learning' (22.2% each). Most frequently selected strategies amongst respondents with up to two years' experience with these children were 'Changing the environment for easy access' (17.6%) and 'Building confidence' (12.7%). Those with three to five years of this kind of experience also most frequently chose 'Building confidence' (21.2%), followed by 'Having consistently high expectations' (15.2%). Practitioners with six to ten years' experience also most frequently selected 'Building confidence' (16.1%). The preferences for practitioners with 16 to 20 years' experience involved six different categories, with 16.7% choosing each of them. Finally, practitioners with the greatest experience of working with children with cerebral palsy, those with 20 years' experience or more, most frequently selected 'Increasing motivation' (18.8%) and 'Providing more time' (16.7%).

The survey also provided two opportunities for practitioners to elaborate – first to indicate further priorities, and at the end to make any other remarks. More than half of the practitioners provided such comments, creating some extended insights into their views about what should be central for nurturing early learning and development of these children.

Some comments related priorities to the micro-context which children attended. They described, for instance, the need for 'a setting which provides a safe, supportive, appropriate, stimulating environment' (early-years practitioner working in a special school's nursery unit), or an 'inclusive setting where children of all walks of life interact' (learning support assistant working in a mainstream reception class). A conductor asserted that the provision should be 'appropriate... to provide support in every/most areas of the child's development'. These views seemed to reflect

particular features of the professional environment in which these respondents worked: mainstream, special or specialist.

Others focused more on the children in these settings and linked their developmental attributes to the characteristics of the setting. For example, one of the early-years teachers working in the Foundation stage of a special school pointed out that 'My class are more capable than some might think as all have profound and multiple difficulties and complex medical needs, but with patience, encouragement and understanding, they are all capable of some independence in their learning and development.' A learning support assistant working for a voluntary organization commented that she was 'working in a group with children with similar needs and difficulties but at different levels of development... [using] holistic approach and the least necessary help'.

Some comments drew attention to the attitudes and attributes which adults brought to the setting, in particular in relation to interaction with the children. For example: 'These children need safe learning, in a positive, caring environment. Teaching staff needs to build confidence enabling the children to feel secure so they can reach their full potential. They need to be constantly motivated, but given the opportunity to develop at their individual pace' (learning support assistant working for a voluntary organization). An early-years teacher, working in a Foundation unit of a primary school, commented: '[It is] important not to treat children differently to other children, just adapt when needed. Have high expectations and don't underestimate what they can do. Allow them to be independent when possible and give individual support to give them space to interact with other children.' Similarly, an experienced early-years teacher working with children both at home and in settings wrote: 'An understanding of individual needs, likes and dislikes. To work with each person using individual strategies designed to motivate and assist.'

Others cited particular processes as being important in influencing conditions for children's development and learning. For instance: 'By giving our pupils a wide and varied experience of activities we hope to enhance all aspects of their individual skills' (learning support assistant working in the nursery unit of a special school). Another respondent advised 'giving children time and being open to all children being individual. One approach does not work for every child with cerebral palsy' (early-years practitioner, working in a children centre). There were a number of comments relating to the need to provide experience which was enjoyable for the children, as pointed out by an early-years teacher working with SEYS: 'Making learning fun, interesting, exciting'. For others the nature of support was more pertinent, such as 'ensuring that they are fully included in all aspects of learning and providing the necessary support to enable this to happen' (early-years practitioner working in the Foundation stage of mainstream school).

Others too emphasized the importance of the social influences derived from being with other children and the ideal conditions for this: 'Acceptance from their peers. Feeling part of a group and being given the same chances to succeed in a full and varied curriculum with careful, subtle support' (learning support assistant working with SEYS); 'To enable the child to feel part of the school community as an individual. Ensure that the child achieves and that it is recognized, praised and encouraged to make the most of these achievements' (early-years teacher working in reception class); 'Discuss the child's needs with their peers and encourage them to engage with/appreciate the needs of a mobility-reduced child. It goes without saying this needs to be done sensitively and at the "right" time' (early-years teacher in mainstream nursery unit).

For some, more important was what happened between the setting and home, or even between the two: For example, a conductor working for a voluntary organization

explained: 'Parental involvement. Parents to receive understandable information of an appropriate quality that they can then adapt into their daily routine'; and from a child minder:

Sometimes parents can be over-protective of their children when they have extra needs and I have found this can hinder their development. Parents can't always see what's best as they are too protective! From my experience I have seen parents treat their children like babies as if they are too afraid to let them learn or communicate, this is very frustrating.

Some respondents took into account broader contexts, predominantly other agencies involved with the child, family or setting itself. A conductor with 20+ years' experience, who worked for a voluntary organization, suggested: 'Communication/sharing information [is important] and agreement between practitioners around the child'; while a learning support assistant working for SEYS wrote: 'A close working relationship with all agencies involved to ensure positive outcome across all areas'. Communication was also cited: 'Regular review meetings to enable all support staff and outside agencies to communicate and discuss progress' (early-years teacher in reception class); also: 'Educating others to be sensitive to the child's needs without treating them as different' (early-years practitioner working for private nursery).

For some practitioners the age of the child was important: 'The children at this setting are two years of age and therefore different priorities apply. While beginning to work towards independence, the focus is on stimulation, motivation and social skills which lead on to learning skills' (early-years practitioner at a specialist nursery). A similar response was provided by the centre manager of a voluntary organization: 'Although eating, drinking, dressing and toileting are essential life skills that we encourage with the children, we do not focus as much on those skills as the children are only 2-3 years old.' Interestingly, a conductor working with a voluntary organization provided an opposite view: 'My point of view is: dressing, toileting and eating-drinking

independently are very important and they should begin to learn it at early intervention stage.'

6.5 Discussion

The variety and complexity of early-years services available for young disabled children and their families was examined in the literature (for example, Wolfendale and Robinson, 2006; Pugh, 2014). The first set of results confirmed this complicated nature within the chosen local authority, not just in relation to provision itself, but also to the multifaceted composition of the early-years workforce involved with children with cerebral palsy.

Results relating to the demography of respondents reflected a female-oriented gender imbalance amongst early-years practitioners also recognized in the literature (Hadfield and Joplin, 2012). Despite the fact that these practitioners worked in a community rich in ethnic composition (Office for National Statistics, 2013), a large majority was from white British backgrounds. Findings also indicated a spectrum of professional qualifications amongst practitioners, ranging from NVQ Level 2 to post-graduate, Masters-level credentials, as well as a continuum of job roles and responsibilities. Within this continuum there were many learning support assistants, reflecting McVitte's (2005) and Richards and Armstrong's (2008) observations of their growing numbers and their increasingly prominent roles in education of children with special educational needs and disabilities.

National policy consensus has for a long time emphasized the need to strengthen professional training for those contributing to inclusive education and childcare (Department for Education and Employment, 1997; Department for Education and

Skills, 2005; Department for Education, 2011). This has been supported also by extensive research (for example, in Buell *et al*, 1999; Flewitt and Nind, 2007, and in the case of children with motor disorders such as cerebral palsy in Brown and Mikula-Toth, 1997; Rose and Coles, 2001; and Rozsahegyi, 2008). However, this survey suggested only a very small number of practitioners had relevant credited professional qualifications. Those who did have these worked predominantly in specialist services, such as SEYS and conductive education, and only rarely in inclusive, community-based settings. For others, professional development derived largely from a range of short-term, non-award bearing courses. However, these courses almost always had little or no specific bearing to work with children with cerebral palsy, relating instead to broader, more generalized areas of special educational needs. Yet in Rozsahegyi (2008) a range of educators was found to welcome more specific, practice-oriented training in relation to work with children with this condition.

Perhaps unsurprisingly, the extent of practical experience varied amongst practitioners a great deal too. Most of those indicating notable experience in work with children with special education needs worked in specialist services, reflecting the historically separate nature of special educational needs provision (Wolfendale, 1997; Lipsett, 2007). Practitioners' levels of involvement specifically with children with cerebral palsy showed a similar tendency. While nearly half of respondents indicated limited experience in this area, those with longer-term involvement with these children worked exclusively in specialist services, such as conductive education, special nurseries, Foundation units of special schools and SEYS. When results relating to professional background, training opportunities and experience were taken into account together, practitioners working in these specialist settings expressed stronger feelings of confidence than those from more generic provisions such as mainstream and private nurseries, children centres, Foundation units of

mainstream schools and child-minding, as one might have predicted. Such multifaceted backgrounds of practitioners have, in the view of Pugh (2014), implications for aims and quality of provision.

When asked about the most important areas of development, regardless of roles, experience and qualifications practitioners gave highest importance to participation in activity with other children and in development of children's social skills, in particular communication. This tendency could be linked to the high priority given to such aspects of practice in national directives (Department for Education Employment, 1997; Department for Education and Skills, 2001; Department for Education and Skills, 2007a) and in recent and current curricular frameworks (Department for Children, Families and Schools, 2008; Department for Education, 2012a). Secondly, it may imply practitioners' desire to see the disabled child being included in peer activities, which would reflect operational ideals described by Wolfendale, (1997) and later by Nutbrown and Clough (2006), whereby inclusion is seen as a process of enabling children's full engagement in activity, rather than their simple physical presence within the setting. Finally, for some it may be a reflection of a basic Vygotskian (1993) perspective on social pedagogy which emphasizes socialization, and in particular interaction (Sutton, 1988; Moore, 2000; Daniels, 2001; Smidt, 2011) as the route for development and learning.

Results concerning strategies for enhancing such development shed further light on this issue. Practitioners with the least amount of practical experience tended to choose strategies of support and assistance which echoed the broader discourse on educating and supporting children with cerebral palsy, namely a focus on environmental adaptation to improve access (Fox, 2003; Tilstone and Layton, 2004; Farrell, 2008; Willis, 2009; Westwood, 2013). Their choice of strategies also implied the child's passive role in activities. In these results prominence was also given to the

role of adults in fashioning a suitable physical environment, rather than to a more interactive learning process which might include both the child's active control and contribution and the adults' psychological and pedagogical facilitation. In this respect, practitioners' emphasis on children's social development may be accounted for more by pressures of policy and curriculum than by any underpinning pedagogical understanding and commitment to the Vygotskian interactive perspective, expressed in relation to current educational contexts by Moore (2000), Daniels (2001), Smidt (2011), Bottcher and Dammayer (2012) and others, and in relation to children with cerebral palsy in particular by Hári and Ákos (1988), Sutton (2000) and Baker and Sutton (2006).

Responses from more experienced practitioners and from those with professional training and qualifications specifically relevant to children with cerebral palsy, most of whom were working in conductive education, indicated strategies involving this more proactive participation by both child and adult. Their main choices reflected this concern: 'Increasing motivation'; 'Providing more time'; 'Having consistently high expectations', indicated greater recognition first that in-person characteristics of disabled children could be qualitatively different to those without disabilities (Vygotsky, 1993), and also that disabled children's had potential to use these characteristics to learn and achieve. Results suggested too that experienced practitioners were more likely to see professional attitude as a greater facilitator of children's learning than simple adaptation and change of the physical environment, the latter in the Vygotskian view being not sufficient to provide developmentally influential experiences (Gindis, 2005).

6.6 Conclusion

In terms of the bio-ecological model, findings from the practitioner survey reflect the four elements in a rather different way to those from the parental survey. The main focus has been on context, incorporating examination of the complicated nature of the workforce in terms of varied qualifications, roles and experience. This complexity linked also to variations in professional perspectives on 'process', namely the kind of strategies felt to be most effective for the child with cerebral palsy, and by extension to 'person', the priorities identified for their development and learning. More extended, additional perspectives are next to be examined, those of local-authority personnel overseeing the provision of special services.

CHAPTER 7: INTERVIEWS WITH LOCAL-AUTHORITY PERSONNEL

7.1 Introduction

Continuing with data analysis, the next four chapters focus on results obtained from qualitative data sources. This chapter begins this process by reporting findings from interviews conducted with key local-authority personnel, representing educational and social support services for young disabled children and their families.

7.2 Aims

Examining the nature and extent of contributions made by local-authority based support services aimed to deepen understanding of multiple outlooks on the early development and learning of young children with cerebral palsy. Becoming familiar with the values, procedures, priorities and challenges associated with these services again helped to address all the research questions.

7.3 Methods

7.3.1 Participants

Participants for the interviews were identified by informing the local authority's Children Services department about the research. Three employees were recommended as the most relevant informants for the study – each managed a different support service for children with special needs and disabilities. 'Tracy' was

head of the Specialist Early Years Service (SEYS), 'Sally' oversaw the Physical Impairment and Medical Inclusion Service (PIMIS), and 'Elaine' managed the work of the Children with Disabilities Service (CDS). Elaine asked to do the interview alongside one of her senior team members, who in her opinion had more extended operational insight into the service, therefore a fourth interviewee, 'Karen', also contributed.

7.3.2 Material

Questions in the interviews were designed to address the following topics:

- a) Key areas and roles of these services within the Children Services as a whole
- b) Procedures and processes by which support was provided for disabled children and their families, including those with cerebral palsy
- c) Intra-service relationships with each other and inter-service relationships with external agencies.

A schedule of interview questions is presented in Appendix D.

7.3.3 Procedure

Written information about the research was shared with participants, together with a broad list of questions, then followed up with a telephone conversation to arrange the interviews. These were scheduled between March and June 2012, but Sally's interview was postponed several times and finally conducted in November 2012. All three interviews were voice-recorded, transcribed promptly, then the text returned to

each participant for data checking. Only Tracy, the head of SEYS, took this opportunity and made some minor, grammatical changes to the transcript.

7.3.4 Data analysis

Raw data was interrogated several times in increasing detail. Initial analysis eliminated information irrelevant to the research questions. Noteworthy or recurring points and issues were then identified. The next level of data processing involved identifying themes, which enabled findings from each interview to be presented in an integrated fashion. Finally, results were organized and discussed with the elements of Bronfenbrenner's bio-ecological framework in mind.

7.4 Results

7.4.1 Interviewees

According to data, all four interviewees had relevant professional qualifications; each also brought ample practical experience and expertise to the service which they were managing. Tracy had trained as a teacher and had broad teaching experience working with a variety of children in local special schools. Sally was also a trained teacher, but had also completed a post-graduate professional diploma to become a qualified conductor in conductive education. She had worked with a range of children with motor-development difficulties, including cerebral palsy, muscular dystrophy and spina bifida.

Both interviewees from the Children with Disabilities Services originally trained as social workers. They had worked in this field for many years and progressed to

increasingly senior posts within the local authority. Apart from their professional qualifications, both had completed management degrees, Elaine at Masters level and Karen at undergraduate.

All four practitioners worked for and were managed by the authority's Children Services. Elaine, Tracy and Sally had strategic roles within this body; Tracy, Sally and Karen had roles with managerial as well as operational components. Elaine explained that she did not currently have any operational or practical responsibilities.

7.4.2 Services

All three services had specialist responsibilities within Children Services to provide support for disabled children and their families. While PIMIS was a long-standing educational department within the Children Services, SEYS, in response to recent Government policy changes, had grown from more conventional Portage work. At the time of the interviews, both SEYS and PIMIS were providing educational support for children with various special educational needs and disabilities. In contrast, CDS was an integral part of the children's division of social services, which provided family support for other groups of vulnerable children as well.

The heads of SEYS and PIMIS considered their services to be affiliated to education, but the two interviewees from CDS associated their service with health and social care. Table 7.1 provides a summary of the basic profile of the three support services, outlining core professional responsibilities and activities within the local authority. This information highlights that only SEYS exclusively focused on supporting pre-school children under the age of five; the other two services provided for children and young adults up to the age of 19. In line with their educational profile, the SEYS and PIMIS teams consisted of staff with either teaching or childcare qualifications,

whereas CDS staff had qualifications and experience in social work and disability nursing. SEYS was concerned with children with cognitive and complex difficulties, while PIMIS dealt with those with physical disabilities and medical needs.

Service	Age range	Key tasks	Profile	The team
SEYS (Special Early Years Service)	0-5 years	<ul style="list-style-type: none"> • Early identification and assessment of children's needs • Home-based, family-oriented early intervention input • Support for various pre-school and early years settings • Maintaining 'specialist' and 'enhanced' nurseries • Staff training for early years professionals • Support groups for parents. 	<ul style="list-style-type: none"> • Communication, behavioral and learning difficulties • Cognitive impairments • Children with complex and profound disabilities. 	Teachers and TAs.
PIMIS (Physical Impairment and Medical Inclusion Service)	3-19 years	<ul style="list-style-type: none"> • Early identification and assessment of children's needs • Home and setting-based support for children • Manual handling courses • Disability-awareness training across the LA • Manual handling training • Disability awareness training. 	<ul style="list-style-type: none"> • Physical impairments • Children with medical needs. 	Teachers and TAs.
CDS (Children with Disabilities Service)	0-19 years	<ul style="list-style-type: none"> • Identification and assessment of families' needs • Maintenance of disability register • Information service • Distribution of direct payment • Short breaks • Safeguarding • Family and domestic support. 	Families with children with various disabilities and additional needs.	Social workers, health-care assistants, disability nurses, family support workers.

Table 7.1: Profiles of local-authority based support services

Tracy described SEYS' principal role within Children Services as incorporating 'early identification and early input for young children with complex needs, support for their families and practitioners working with them in various early-years settings'. Sally provided a similar summary for PIMIS: 'We work directly with children in mainstream and special settings, providing various training courses, monitor children's progress and development and support for parents.' Elaine, the head of CDS, summarized her

service: 'Broadly speaking our role is to go out, assess families, and determine what the need is to enable that family to stay together safely and to have their needs met.'

Apart from input for children and their parents, the remits of SEYS and PIMIS also included practical work in a range of pre-school settings, as well as provision of continuing professional development opportunities, including training courses, for staff working in these settings across the local authority. CDS appeared to approach children's support from a different angle. First and foremost this service provided tailored support for families with the aim of improving conditions for parenting and upbringing of disabled and other vulnerable children. They also maintained the local disability register, a legal requirement for Children Services as a whole.

7.4.3 Referrals

Closer insights into professional obligations were obtained when specific processes and strategies were discussed. All three heads described an open referral system, explained by Tracy: 'Anybody can refer – settings, other professionals, parents.' Sally was rather more specific: '[PIMIS is] not diagnostic dependent – anyone can refer to us. Parents refer, schools refer, consultants refer, other services refer, SEYS refer. However, we like to see the children before we do consider taking them on our caseload.' Referral and assessment seemed to go hand in hand within her service.

Elaine from the CDS talked about a similar system: 'In real terms parents and carers, nurseries and schools, counselors, nurses, hospitals, doctors... anyone provided they've got the consent or they are the person themselves, anybody can refer in.' More specifically for disabled children, Karen explained: 'We'll be the first point of call for the neo-natal unit from M.'s Children's [regional children's hospital]. So it is the medical profession, particularly where they've got concern, or the health visitor's

concerns about how the family is adapting to the life-changing event.’ CDS was usually the first point of external contact for provision of support in response to professional or parental concern. For some parents, as reported by Karen, this could be as early as when mother and baby left the hospital, soon after the child’s birth.

Tracy, speaking from the point of view of SEYS, was rather critical about this kind of open referral system:

I don’t think the system is completely water-tight. Children would normally be picked up at latest when they get into a nursery. But the ones that we throw our arms up in horror and say “How an earth did that child manage to slip through the net?”, it is often where parents are not accepting that their child has got a difficulty, and therefore have been keeping people at arm’s length. Because obviously to refer to us you do have to have parents’ permission. If parents say no, then there is nothing we can do.

In this instance, Tracy was not questioning the competence of professional services, but highlighting one particular reason for delay in early intervention, the attitudes of some parents to their child’s disability or developmental difficulty. Karen also made reference to parents in relation to CDS referrals:

I would say you get peaks at children’s transitional points. So it’s not uncommon at around about three months, as the reality for some families is really hitting home. And these parents may have other issues, that either the child is so profoundly disabled or needing a continuing health-care package. So those we will get quite early. The next equal peak is when the children are starting school ... but we have them coming through all the time. I don’t really think it is age-specific.

Data also suggested that referrals for the two educational services came predominantly through professional recommendations, whereas for CDS it was more a combination of professionals and parents initiating contact with the service.

7.4.4 Assessment of needs

The next topic related to the process of assessing and identifying children's needs and making recommendations for provision. The two educational services followed a similar process. Sally reiterated her earlier comment that PIMIS was not dependent on diagnosis and did not have explicit criteria for admission: 'We have an open assessment system, meaning that a child does not necessarily have a diagnosis, but when a child's physical or medical need is impacting them to access education whichever way, we will work with them.' This seemed to suggest, perhaps paradoxically, that children did not need a medically endorsed diagnosis, but that their developmental difficulties needed to be predominantly physical or medical in nature for them to receive support. She explained the grounds on which children were divided between PIMIS and SEYS: 'Tracy's service sees children who've got complex needs, children really with cognitive delay. We see children who have not got cognitive difficulties or who've got a medical problem.'

Tracy confirmed this agreed inter-service principle: 'If it's a purely physical need and there's no cognitive impairment, then PIMIS team would see them, so that would be a separate provision. So we only see the ones who it is felt have got some degree of learning difficulty as well.' When these difficulties were more dominantly sensory, then children were referred to other educational support services also located within Children Services, such as the Visually Impaired or Hearing Impaired Support Services.

In relation to how and by whom such division of needs took place, both managers referred to their own assessment processes, showing similarities in the way they identified children's needs. Tracy explained their process for younger children:

If the children are at home, then obviously it's down to the information that's been given by the referee. Sometimes that is very good, so it might have come from a paediatrician and you've got all the history there and everything you need to know. Sometimes if it is a parental referral, then obviously it is their concern, it won't be necessarily anything medical, it won't have that sort of history in it. So it is important to ask parents' permission to talk to anybody else that has been involved ... but remembering that parents know their children best and they often give you the best information.

She added that the overall assessment process was not a one-off event, but based on a series of visits, usually six, at the end of which recommendations were made for home-based or setting-based input by the SEYS team or for transition to another service within Children Services. When prompted, Tracy also revealed the focus of this assessment process as 'areas of development, so we would look at their language, social development, their fine and gross motor skills and the cognitive side of skills, so we would look across the board'.

The similar assessment process for PIMIS was described by Sally thus:

We talk to the parents, see the child. You know you have to look at the child, find out the background, try and piece together which medical professionals are involved, because we obviously need that back-up. So just to get a picture of what's going on, where we are heading, sort of plan what we need to do. Then either go to speak to others, like SEYS, or go to see the child in the setting. It depends on the age of the child.

The role of CDS in assessing and identifying disabled children's needs for educational provision was not so direct. Elaine explained that they contributed to assessment only when asked to do so by SEYS or PIMIS. On a more operational level, however, as Elaine emphasized, the authority itself is 'very stable with people who worked in and around this authority for a good many years. I know Tracy, I know the Dr. G. [consultant paediatrician], so we walk around with this intelligence of who to refer to and when and that works well.'

In relation to CDS, Elaine described a more complex and prescribed system, one which needed to be in line with relevant national legislative frameworks:

Nurses use the CAF [Common Assessment Framework] assessment, a behaviour assessment and a sleep assessment. Whereas social workers will do a 'call' assessment according to the National Assessment Plan, to find out how the family copes with parenting, household duties, stress, but also about housing and financial needs... Apart from this, assessment is about safeguarding children ... assessing the level of risk in a family or the level of support the family needs to prevent them breaking down.

7.4.5 Graduated response

Both Tracy and Sally described a process of graduated response to children's needs, following assessment. Sally from PIMIS explained that early intervention 'depends on the child's age, needs and what type of provision they are accessing', because 'they have to have the right support, both for the child and for the setting, so they can start attending as soon as possible'. Children could receive help from the specialist teaching assistant at home on a weekly basis, or, depending on the children's age, needs and the type of setting they attended, either a fortnightly visit in the setting by the specialist teaching assistant or a session with the specialist teacher once a half term. She continued:

Ten years ago our core children would be statemented. So in the past we provided support in line with the Statement of Special Educational Needs. However, these days lots of children don't have the statement and therefore they need lots of support through the settings they attend.

In line with Sally's explanation, Tracy from SEYS reiterated the process of identification of needs within the local authority:

The norm is that children aren't statemented for their nursery provision because SEYS and PIMIS provide the support that the children need, so on the whole we usually start the [statementing] process about nine months before they go into school. The exception to that would be children where there's a medical need which means they actually need someone one-to-one to maintain their safety in a setting.

Tracy elaborated on the process of establishing adequate and timely provision: 'If the child is young and does not attend any setting, it is usual to start off by giving input to children in their homes, which also gives opportunity to talk through our strategies with parents and show them some simple ways how they can play with their children, how to encourage communication or independence.' When children progressed to attending pre-school provision, the nature of the support changed and children received input from the SEYS team 'once a fortnight if they are 0-3, and if they're in a nursery, that would depend which nursery they are in... It can range from five 50-minute sessions a week with a specialist TA [teaching assistant] or one session a week with the specialist teacher.'

Sally identified an ongoing challenge in relation to her work: 'There is a group of children we don't have provision for... they are physically very, very disabled but very bright, for instance, some children with cerebral palsy. But they don't fit into the straightforward category of MLD [moderate learning difficulties] or SLD [severe learning difficulties] schools.' She added: 'To certain degree we are able to meet their needs in mainstream settings, but actually we have to be more sensible and recognize that there are other people who've got more expertise.' She reported that in these cases PIMIS may seek out-of-authority placements. In the past this was a frequent solution, but due to current cutbacks in funding the option has become almost impossible.

7.4.6 Multi-agency work

Interviewees repeatedly made reference to working with others, both within and outside their professional fields. However, such collaboration was more evident when they described their professional activities with external agencies than when they talked about Children Services itself. All three participants confirmed that their specialist service was recognized and recommended by professionals working for agencies external to the authority.

Tracy explained this joint multi-agency work at both strategic and operational levels. Strategic collaboration was part of her managerial role: 'I sit on management boards with health managers, we meet up with the paediatricians, physiotherapy manager, occupational therapy manager, speech therapy manager.' She tended to describe collaboration from a planning and monitoring point of view: '[Other professionals] are involved in our reviews, they refer to us, we refer to – no we can't refer to them actually ... We work very closely with the therapy service and often do joint home visits. Even if the child is not on early support, we tend to do joint reviews.'

Sally explained PIMIS' participation in multi-agency work in a more reserved way: 'We liaise where we need to... Meetings bring everybody together.' On a more critical level she also highlighted the challenges faced by herself as a manager and by her team in relation to such joint working:

To be honest we have to come together for action planning ... so we are not duplicating work... For instance, we don't need three people to do an access visit... But on the other hand during meetings we go round and talk about what each of us is doing and what we need to be doing, then everyone feeds into this.

Sally continued:

Although collaboration has improved over the years, and indeed early intervention helped with this a lot... everyone works within their own profession. You've often got policies of different departments and different professionals that tell them what they can do or should be doing. Some people are more flexible than others.

Difficulties arose for her service for a number of reasons. Differing policies and procedures could interfere with smooth collaboration:

The challenge is just different people's waiting list and the pressures of their own profession... So for instance we really struggle for speech and language therapy at the moment... Their waiting list is very long so we cannot provide that input for children as we would have wished to.

Tracy also highlighted difficulties, including differences in professional priorities:

...because we look at children's development and learning from a holistic and educational point of view, and they do things from a different discipline's point of view... For example, a physiotherapist would not do this, they would only focus on children's physical development.

Elaine explained that in CDS human resources, the volume of caseload, staff shortages and lack of time were the greatest barriers to working with other agencies. Karen, on the other hand, highlighted 'senior management's perception, society's perception, of what the CDS do in the greater scheme of society'. Illustrating her point, she continued:

If you've got your cake to carve and you've got your children with mental-health issues who needs safeguarding, you've got your looked-after children, you've got young offending children, travellers, disabled children... you have to really fight for every cause. It would be too easy for us to be missed. That's what you spend a lot of time doing, just promoting this disability support service and fighting our corner.

She also commented: 'In the old days... adults came first, children came last. And children with disabilities were at the bottom of the pile. And it's still a little bit like that.' Elaine shared two other aspects of their core work: responsibility for

overseeing short breaks and maintaining the local authority's disability register.

According to Elaine, short breaks benefited both parents and children:

[They are] allocated on the grounds of complexity of needs and family circumstances, which is overseen and allocated by the CDS team... When needs are less complicated, funding may be used more flexibly, for instance there is short-break funding. That's being directed into some of the provisions, so that the families or, if the child is old enough, themselves can choose.

Selection for this family support was based on 'a menu which we've developed to help to categorize the sort of needs into a numerical value.' Yet, according to Elaine, providing a personalized and fair system of social support was problematic:

Disability cuts across every social class and with that you will have some parents who would never want any support from anybody... We have families that really need support, but won't ask, either because they feel so downtrodden that they don't feel they are worthy of support, or they haven't got self esteem or whatever... Then you get parents who are very well organized and articulate. They make reference to Children Acts and they know their entitlements.

One means by which this imbalance was addressed was with the disability register. Apart from the legal duty of collecting demographic information about families with disabled children, the manager of CDS saw this also as the way to identify families with broader support needs. However, this too had its challenges. Firstly, as Elaine pointed out, entry on the register was voluntary for parents. Secondly, she suggested that 'any register system is only as good as what is inputted and what's important to the family. So if the family are describing the child as having cerebral palsy, then that will be recorded ... More often than not, the child will be described as having a severe learning disability or a visual impairment, rather than cerebral palsy.' She doubted the usefulness of asking for this type of description, wishing instead that the register had greater focus on practical impact: '[Does] the disability or the health condition that the child's got affect their day-to-day functioning?'

7.4.7 Support for settings

The work of SEYS and PIMIS also involved collaboration with and support for maintained and non-maintained childcare and early-years educational establishments. Both managers talked extensively about how their services provided practical guidance and formal training in these settings. This element was not evident in the CDS account.

Tracy, from SEYS, highlighted increasing demand for this aspect of their work and suggested a number of possible reasons for this:

We work more with the private and voluntary settings that had never really experienced children with additional needs, and when they were given the nursery education fund, it was a requirement that they had a special needs co-ordinator... Obviously more and more parents are choosing to have their child's nursery education funding in private and voluntary settings, because it fits in with a working mother's life.

She also highlighted high staff turnover amongst young and inexperienced practitioners and a steady increase in the number of children with additional needs. She felt that these needs were becoming more complex and cited anecdotal evidence of 'the increased number of premature babies and of those conceived through artificial means'.

Sally shared a similar view in relation to PIMIS. She emphasized the difficulties which private and voluntary settings experienced because of limited staff understanding of how to meet the needs of disabled children. She also distinguished between maintained and non-maintained settings in relation to funding opportunities and in particular to staff training and the building-up of adequate setting-based resources: 'Private settings have general issues around funding, they generally have more unqualified staff in a caring rather than educating role. It is more difficult to get

training in, more difficult to get them to understand the children's needs and to promote their learning.'

Elaborating on this view, Sally explained that '[private] settings are really good to let children play and with the social aspect', but, staff 'need to move from a caring role and to understand how these children can develop and learn... We try to model this to them in all sorts of ways, for example taking part in the practice and modeling, finding solutions for problems.' She highlighted how some settings could be prone to 'prejudices towards disability, staff's varied enthusiasm and attitude and very often the problem of very low expectations towards these children'.

Physical management, as well as a lack of staff experience of work with disabled children and issues surrounding communication with their parents, was also a noteworthy concern for both maintained and non-maintained settings. Tracy expanded:

I think the most common one that we get is fear of the unknown which often comes with the label or diagnosis of the child... Often when they know the child since she or he was a baby, for instance through older siblings already attending the setting, that fear often goes, because the child is somebody they know as opposed to a label which comes with diagnosis.

To address these difficulties, SEYS and PIMIS offered practical guidance, modeling and general reassurance, as well as formal training and professional-development courses. SEYS, for instance, offered SENCo training for early-years practitioners within the local authority, also courses with a specific focus, such as children's communication or use of the signing system, Makaton. PIMIS on the other hand provided disability-awareness training, safe moving and manual-handling courses, as well as sessions on specific medical and neurological conditions. These local-authority courses were free to all practitioners working within the local-authority area

and there was no limitation on how many such courses practitioners could sign up for.

7.4.8 Parents

The most important type of collaboration involved services' support for and work with parents. All four interviewees claimed to work closely with parents in this respect. In all three services the relationship commenced with a home-based assessment visit to identify the child's and family's needs. The managers of SEYS and PIMIS explained that either their specialist teachers or their teaching assistants worked with children in their homes, alongside mothers and fathers. For under-threes with SEYS this was the main form of provision until children began to attend childcare or pre-school provision.

There were other forms of collaboration with parents too, such as joint reviews, with staff acting as key workers. Sally pointed out that parents 'do phone up with problems, some people just phone up to have a chat or parents who would not talk to the setting itself', indicating her service's informal counseling role. Tracy also described this process: 'All staff have a mobile phone and the number is shared with parents. They can text or whatever, but they don't need to wait to catch the practitioner in the office.'

The main remits of CDS, as a different kind of local-authority based support service, were establishing and sustaining more regular contact with parents in order to enable them to fulfill adequately their parenting roles. This contact mainly involved help to solve social, financial or domestic difficulties, and even seeking to resolve conflicts with other services in contact with the family.

Interviewees from all services did not shy away from sharing more problematic aspects of their work with parents. For instance, tensions could arise from differences in opinion. As an example, Tracy reflected on the process of selecting appropriate early educational provision while also maintaining a longer-term view:

If we professionally feel that this child needs a special nursery or school, and parents are insisting on mainstream school, they will get their mainstream place. But we will indicate on the paperwork that it is our professional opinion that they need a specialist educational provision... Sometimes we are wrong, sometimes the parents were absolutely right or the child actually is doing fine there, yet they might have done better if they'd gone into a special nursery.

Sally described other typical scenarios, including contrasting views on the child's maturity, disability or expectations for their development. She gave an example:

Parents obviously use buggies for their young children, when they go to nursery. However, some children go to school when they are four. The school is a very different ball game to the foundation stage and I present them with the issue of buggy versus wheelchair. With a wheelchair you can develop independence while the buggy is the symbol of babyhood, but not the symbol of disability... Thus what is used for transport will adversely affect perceptions about the child. Some parents think it is acceptable to take their children to school in a buggy.

For CDS the problematic aspects of working with parents were rather different. At an immediate level CDS wanted to reach out to more parents and carers, so that they could receive more information and support in line with their entitlement. To address this, as described by Elaine, the service continually 'develops new ways of distributing information, for instance through posted newsletters, through their own and others' websites, but even to go to parents' evening and community events'.

Once parents became part of support systems, other challenges arose. For instance, CDS recognized that long-term involvement with a particular family of a single member of staff could mean that important issues could be overlooked. While

continuity was important in many cases, sometimes there was a need to change the support worker involved. Some parents would reject this step, however: 'They don't want to change... They have so many people involved in their lives, they just want a person to stay with them as long as they can and is needed.'

7.5 Discussion

The interviews with managers highlighted roles, procedures and strategies of the three local-authority based support services and participants' perceptions of their operational elements. They also showed how young children's disabilities and impairments were perceived within these services and the means by which children with cerebral palsy were allocated to provision.

All four participants understood the appellation, 'cerebral palsy', but all also resisted the idea that provision was dependent on diagnosis, insisting instead that it was based on assessment of needs. Sally, head of PIMIS, used the 'cerebral palsy' term repeatedly. Others tended to make reference to categories of needs, such as 'children with physical needs' or 'children with communication needs', perhaps in an effort to remain consistent with the terminology used in national directives, such as the SEN Code of Practice (Department for Education and Skills, 2001). However, when procedures and practices were discussed, in particular with the managers of SEYS and PIMIS, interviewees used the notion of 'needs' interchangeably with that of children's 'difficulties'.

For CDS the situation appeared even more uncertain. Information about the complexity of a child's disability and the nature of developmental difficulty, which was

fed first into the local-authority based disability register, then incorporated into national statistics, was supplied by parents on a voluntary basis. The manager herself questioned the reliability of this information, suggesting that children with cerebral palsy could be recorded under other labels. This echoed the tensions evident in the literature in relation to the reliability of disability registers at local and national levels (Parkes *et al*, 2001; Mooney *et al*, 2008).

Multi-professional and multi-agency collaboration was an important theme in the interviews, as specified in relevant legislation examined in the literature review. All three managers stressed the importance of contact with medical professionals who made referrals to their services and supplied expert information about the children's medical backgrounds. However, the means by which such collaboration took place were described rather differently by the interviewees, perhaps signaling ambiguity of policy or differences in professional priorities or outlooks on children's development and learning.

Tracy, from SEYS, relied on expert medical and therapeutic advice, which was then complemented with information deriving from her service's own assessment and identification procedures. Sally at PIMIS appeared to be more reliant on her own and her team's observations and assessment than on medical input. For CDS, establishing prompt and proactive contact with families, in particular with those experiencing difficulties, was a basic prerequisite for fulfilling the service's support and safeguarding obligations. According to Elaine, this could not happen without close collaboration with medical professionals working at different levels of the health system. Despite differences, however, the three services all showed in one way or another operational reliance on other professionals. This approach echoed the

broader view of the literature, namely that the most proficient way of meeting diversity of needs is a multi-agency and multi-professional approach (Carpenter, 1994; Roffey and Parry, 2014).

Such inter-professional collaboration linked the two educational services to therapeutic agencies, for instance speech and language therapy, physiotherapy and occupational therapy. However, interviews suggested that this was mainly focused on strategic processes, such as shared planning or reviews. Examples of possible operational collaboration on home visits or assessments were largely absent from the data.

The challenges of collaboration described by Aubrey (2014) included practitioners' adaptation to different professional contexts, hierarchies and agency cultures. Managers of the two educational services indeed highlighted differences in professional priorities. However, two interviewees also suggested that as the authority was small and as the same professionals had been in managerial and strategic posts for some time, they were well aware of each other's services and felt comfortable working together with other professionals from different professional fields.

Another kind of collaboration, of very high priority, was with early-years settings. Heads of the two educational services, SEYS and PIMIS, perceived an increasing need in these micro-contexts to strengthen further their work with disabled children and with others with additional needs. Demand for professional input from their services derived from a lack of training, experience and awareness amongst setting

staff, the absence of relevant teaching strategies used to support these children, high staff turnover and insufficient financial resources.

While the role of voluntary organizations as a source of expertise and resources for disabled children is recognized in the literature (Miller, 2000; Pugh, 2014) and continues to be emphasized in recent national policy (Department for Education, 2010; 2011), findings canvassed a different picture. There was a consensus amongst the interviewees that professional support was needed more in voluntary and private settings than in those maintained by the local authority.

Finally, the most influential micro-context with which these services had contact was children's family and home. For all three services this was their first point of contact in relation to the child and the context for initial assessment and identification of needs. Early support for under-threes was exclusively provided in the children's homes in recognition of parents' role at such young age. Even as the child grew older and attended setting-based provision, working with families was a key part of the overall support strategy, sustained through continuing contact with their home contexts.

From an educational point of view, SEYS and PIMIS also recognized the necessity of working not simply with the child, but also with parents themselves. Their practice therefore seemed family- rather than child-centred (Heinicke *et al*, 1988; Guralnick, 1991), in ways recognized and prioritized in recent and current policy frameworks examined in the literature review. CDS also had strong concern for this kind of relationship, but in a different way. For CDS the key priority was not specifically educational, but focused more on improvement of the circumstances for parenting,

so the child's well-being could also be improved, echoing similar intentions projected by Crittenden (2005).

In all cases practical work with parents carried challenges. Tensions were evident at both planning and operational levels and, in the views of the local-authority interviewees, often derived from differences in opinion regarding the child's needs and disability. They were also evident in relation to longer-term issues, in particular for the two educationally oriented services, for instance when making decisions about the provision in which the child should start their setting-based education. Another example was when parents' requests could not be fulfilled due to lack of resources within the local authority. For children with cerebral palsy and their families this was a particular problem. Sally, from PIMIS, saw them as children without suitable educational provision – their complex physical difficulties could not be addressed in mainstream settings, but special provision would not adequately cater for their cognitive needs.

7.6 Conclusion

In terms of Bronfenbrenner's hierarchy of contexts, the three local-authority based support services represented exo-level professional environments, located in between micro-contexts and more distanced, policy-initiating macro-directives. The services were often engaged in meso-level activity involving parents or early-years settings.

Results once again related to the four elements of the bio-ecological model as a whole. Decisions about service provision within the services involved interpretation

and categorization of children's impairments and needs, providing exo-systemic perspectives on 'person'. These were especially relevant for children with cerebral palsy, given the particular difficulties they presented within this system. 'Context' and 'process' were evident in descriptions of the main professional activities of these support services, with the two educational teams, SEYS and PIMIS, working with children and families at home and with professionals in childcare or educational settings, and CDS more focused on the family, with no real involvement with children themselves. The fourth concept of 'time' was evident in discussions about provision for children's future education and management of their transition. The study now moves back to parents, analyzing deeper perspectives of a selected group, derived from interview.

CHAPTER 8: INTERVIEWS WITH PARENTS

8.1 Introduction

Following analysis of outlooks of a broad community of parents and early-years practitioners, together with more specific viewpoints of three local-authority personnel, the study now scrutinizes more detailed perspectives of a small number of parents – mothers and fathers – on their experiences in relation to their own children.

8.2 Aims

This chapter reports findings from six parental interviews. The complex and unique experiences of these parents bringing up a disabled child made this small group of participants key informants in this study. Data gathered through interviews deepened understandings derived from the parental survey, contributed to answering all research questions and helped to triangulate evidence derived from other data sources.

8.3 Methods

8.3.1 Participants

The interview sample was drawn from the parental survey. Maximum variation guided the sampling process, but this related more to the children's characteristics than to parents themselves – selection was made on the grounds of their age and

gender and the type of provision they attended. Table 8.1 provides an overview of the final sample and its overall characteristics.

Parent(s)	Child	Child's age	Child's provision	Other children in family?
Jo & Steve	Emily	3 years 11 months	Private nursery	No
Mary	Dan	4 years 10 months	Conductive education	No
Claire	Zack	2 years 6 months	Children centre	Yes (older brother)
Lynn	Chloe	3 years 10 months	Special nursery	Yes (older brother)
Cath & Neil	Mia	4 years 11 months	Mainstream reception	No
Lucy & Mike	Lily	1 year 10 months	SEYS home input	Yes (older brother)

Table 8.1: Characteristics of sample for parent interviews

Both mother and father were interviewed in relation to Emily, Mia and Lily. Dan, Zack and Chloe were growing up in single-parent families, thus only their mothers contributed to the research. Three of the children had older siblings; others had no siblings. Two parents, Jo and Mary, had professional experience working with disabled children – this informed their responses to interview questions. Three children already had a Statement of Special Educational Needs: Emily, Dan and Chloe.

8.3.2 Material

Interviews pursued three main topics (Appendix E):

- a) Parents' experiences of the circumstances of their child's very early development and learning;

- b) Parents' perspectives on current arrangements for childcare, early educational input and additional support, and the degree of their satisfaction with such arrangements;
- c) Parents' priorities, aspirations and desires for their child's future.

The interviews provided opportunity for personalized conversations with parents about these topics, indicating also parents' outlooks on how cerebral palsy affected their children. It also conveyed their concerns about bringing up their disabled child.

8.3.3 Procedure

Interviews took place between May and October 2012. Once research information had been shared with the parents, interviews were arranged at times convenient for them. All were conducted in the families' homes, some while the child was present, others in the evening while the child was asleep.

All interviews were voice-recorded with consent and transcribed soon after. Transcripts were returned to parents for data checking, enabling them to review their narratives and to add or remove elements if they wished – none did this.

8.3.4 Data analysis

Interrogating the interview material was analogous to analysis of data from the local-authority interviews described in the previous chapter. Data reduction first eliminated irrelevant information; outlooks pertinent to the research questions are interrogated here. This approach maintained consistency between analysis of different data units within the overall study.

8.4 Results

8.4.1 Parents and children

All parents interviewed were bringing up a disabled child under the age of five. Although these children shared a diagnosis of cerebral palsy, their individual needs, the extent and complexity of their difficulties and the means by which these were addressed through parenting, childcare, early educational input and additional help were diverse. An initial pen-picture was drawn up of each child from the interviews. These conveyed parents' perceptions of the overall characteristics of their child and the contexts within which childcare, early education and additional help were provided. They are presented here.

a) Emily

Jo and Steve are parents of Emily, aged 3 years 10 months, the only child in the family. They described their child as a happy and confident little girl, who enjoys social activities and being with people, especially with friends in the nursery. Her favourite activities include colouring and painting; she likes going to the park, using playground equipment and feeding the ducks. Parents reported that Emily often gets frustrated with challenging physical activities and will demand help from adults when faced with them. Loud noises or very busy places distract her from her activities – she 'freezes' and becomes withdrawn.

Emily was described as being slightly delayed in areas of personal, social, language and cognitive development. Her parents were most concerned, however, with her physical development, in particular her mobility. Although Emily has begun to walk

independently, her Dad highlighted her lack of confidence when moving about. She currently uses a walking frame to increase this confidence.

Emily attends a private nursery part-time and receives input from the Physical and Medical Inclusion Team (PIMIS) within this setting. She also receives weekly input from a physiotherapist and attends speech and language therapy and hydrotherapy fortnightly. She has less frequent educational support from the Specialist Early Years Services (SEYS).

b) Dan

At the time of interview Dan was 4 years 10 months old. He is brought up by his mother, Mary. She introduced Dan as a generally healthy little boy, who is developing slowly but steadily. His favourite activities are swimming and playing with his adapted computer. Mum described Dan as having global development delay in which physical difficulties are most pronounced, hindering him in many activities. He also has difficulties with cognitive, language and social development. Recently he has learnt to crawl around, improving his access to the environment and reducing frustration. He vocalizes to indicate his wishes or dislikes.

Arrangements for Dan's early education involve combined placements. Two days a week he attends a special nursery, where he is supposed to receive weekly physiotherapy, speech and language therapy and occupational therapy, although Mum questioned the regularity of this input. On the other three days he attends conductive education, where he participates in more extended specialist development programmes.

c) Zack

Zack, aged 2 years and 6 months, is similarly brought up by a single mother, Claire, who also parents his older brother. According to Claire, Zack is a happy little boy with strong desires. His favourite activity is playing with toy cars, but he is also fascinated by electric objects which move or make noises. Playing rough-and-tumble games with his brother gives him great pleasure as well.

Claire described Zack's disability as severe cerebral palsy, which impacts only on his physical activities. She argued that his understanding and speech were appropriate for his age. He is a little short-sighted. In the past Zack has had prolonged medical difficulties, often spending time in hospital. However, these have recently been resolved and he is healthy now.

Currently Zack attends nursery in a children centre three whole days a week. There he receives physiotherapy, speech and language therapy and input from a teacher for visually impaired children and from SEYS – however, Mum (similarly to Dan's mother) was not confident about the amount or regularity of these various services. At home Zack has a walking frame and special seating arrangements for feeding and playing.

d) Chloe

Chloe, aged three years and ten months, lives with her mother, Lynn, and her older brother. Lynn described her as a happy, funny and generally placid child with a very strong personality, who 'just does things what you wouldn't expect her to do'. According to Mum, Chloe has developed slowly and needs time to get used to

people and places. She loves being with her teenage brother, in fact the only proper word she says is his name.

Mum said Chloe needs assistance with most things. Although she has recently learnt to move about on her knees, she still requires help with feeding and dressing; her communication is non-verbal, although she can use her voice to indicate her needs. According to Lynn, 'Chloe may appear to be very disabled, but she does understand a lot of what you say. Whether she wants to listen is a different thing.' Chloe also has severe epilepsy and hearing difficulties. She has been provided with a wheelchair and a special chair to help with daily care.

Chloe recently started to attend the nursery unit of a special school, building up to full-time placement next school term. Mum reported that Chloe receives the greatest input from her teacher; she is also helped, less frequently, by the physiotherapist and by the speech and language therapist.

e) Mia

The interview about Mia, aged 4 years 11 months, took place with her mother, Cath, and father, Neil. Both parents saw Mia as a very determined, strong-minded pre-schooler, with a strong imagination and interest in acting, role-play, singing, dancing and the world of fairy tales. However, she becomes frustrated when she is unable to do something physically or cannot pursue what she wishes to do.

According to her parents, Mia's cerebral palsy impacts predominantly on her walking. Mia has recently learnt to maintain walking balance, but although she can move about independently, she often falls. She also experiences difficulties with use of her right hand during fine manipulation activities, such as writing. Her parents feel that

her independence is developing well, but academic progress falls behind their expectations.

Mia attends the local reception class where an allocated, one-to-one teaching assistant helps her throughout the day. In her parents' view, Mia currently copes with the social, emotional, physical and cognitive aspects of being with her peer group, but Mum, being a primary teacher herself, questions Mia's ability to cope with increased academic demands in the future.

f) Lily

Lily was the youngest amongst the target children, aged just 1 year and 10 months. Both mother, Lucy, and father, Mike, reported that after a difficult first year, Lily has started to make steady progress in many areas. They described their daughter as a happy and contented child and a loving sister of her older brother. Recently her personality has begun to emerge – a strong will and stubbornness to pursue her wishes. She likes playing with others, but increasingly engages with toys. This kind of play has become more possible since she learnt to shuffle around on the floor.

In terms of her disability, Mia's parents felt she has many difficulties, the greatest of these being her mobility, use of hands, understanding and communication. Mia receives input every six months from the SEYS specialist teacher and is also visited fortnightly by the physiotherapist and the speech and language therapist. At the time of interview Mia was looked after by Mum at home, but the family was planning for a possible nursery placement.

8.4.2 Earliest development

All mothers reported that after a problem-free pregnancy, they had not expected any difficulties with their baby's biology or development. Zack, Lily, Mia and Chloe, however, had serious medical complications during or after birth and consequently remained hospitalized after birth. For Emily and Dan, no early medical or developmental difficulties were evident.

For the four children with serious, early medical difficulties, the first concern was inevitably to save life and establish basic biological functions – for instance, for Zack proper digestion and feeding, for Mia and Lily independent breathing and heart functioning and for Chloe control of seizures. The mothers of Dan and Emily, on the other hand, began normal parenting, establishing mother-and-baby routines and gradually learning more about the characters of their new child.

8.4.3 First concern to diagnosis

For the children who remained in hospital, there was opportunity for their parents to discuss with experts their child's immediate and longer-term prospects for development. All four families recalled being provided with a 'worst-case scenario'. Lucy, mother of Lily, remembered hospital staff suggesting that 'she'd either not live or if she would she had severe cerebral palsy...she will probably never walk or feed herself, she'd be probably blind and deaf, she'll probably never recognize you and she will not do anything'. When Lily finally went home from the hospital, this perspective was echoed by the health visitor, who in Lucy's words, 'was absolutely useless... her words were: "Well, I've dealt with a baby like Lily before but she died"'.

Lynn, mother of Chloe, had similar experiences. She was told in the hospital that Chloe had so many difficulties, “just give up reading about them because it will only upset you”. She was told that Chloe was brain dead, she would never recognize her mother, ‘she would never smile, would never sit, she’d never walk, basically she was a complete cabbage. You can imagine it was absolutely devastating.’ In relation to Mia, Neil, from a father’s point of view, described the conversation about his daughter’s progress with medical professionals as ‘horrendous’. His wife, Cath, explained in more detail: ‘They gave me the worst case, she won’t be able to walk, she won’t be able to hear, won’t be able to do anything... Pretty much they used the words: she can’t see, can’t talk, can’t move, won’t be able to talk, complete vegetable.’ Claire, Zack’s mother, reported that specialists were at least optimistic about her son’s recovery from medical difficulties. However, in relation to his development, they suggested that ‘there might be something mentally wrong with him. They said he might never walk, but if he ever does he’ll need assistance.’

Parents of the other two children, Emily and Dan, experienced a rather different professional outlook. Jo described reactions to Emily’s early difficulties with feeding, when her general development was slow: ‘I kept going to the health visitor saying that “she is still not doing this or that” and they said, “oh, don’t worry, she is just delayed”, but we always knew something wasn’t right.’ Dan’s mother, Mary, also had concerns over her child’s development, a perspective informed by her own professional experience with disabled children and which led to her making an appointment with the GP: ‘First I noticed he was not making eye-contact at three months or tracking a toy or anything, and he was not smiling when he should be smiling ... and it took a long time to learn to control his head really.’ The GP gave a similar response to that given to Emily’s mother – the problem was Mary being anxious, rather than with her baby.

For all parents, therefore, the first weeks and months – the time when initial bonding with a child usually takes place – were not smooth nor a positive experience. Anxieties about their children's difficulties – medical or developmental – inevitably brought them into very close contact with a range of medical contexts: hospitals, GPs, health visitors. The first experiences of parenting their baby, influenced by expert others, incorporated either pessimism for the future or an optimistic disregard which seemed at odds with perceived reality.

The process of finding a medical label for children's difficulties also varied amongst the six families. The age at which cerebral palsy was diagnosed varied from 4 months and 1 year 8 months. All parents, apart from Mia's, experienced a time lapse between when they or others had their earliest concerns and when they received confirmation of their child's disability. Parents perceived this time as filled with examinations and assessments.

Diagnosis was the end point of this medically determined time-span and had varied significance for parents. For Emily's Mum, it was 'just like a bombshell, she has got CP. We were not prepared for it because they kept telling us everything was ok ... we believed them that she will catch up'. Cath, Mia's mother, recalled: 'We knew there were issues because of the prematurity and the brain hemorrhage, but we expected to hear more about her cerebral palsy than the simple advice to take each day at a time with her development.' Mary talked about the series of tests done to her son, Dan. Instead of informing her of the results, 'they just tried to pass it off all the time'. Mike, Lily's Dad, described the hospital's response to queries about his daughter's development:

They would not commit, that was the most frustrating thing. Nobody would commit to tell the long-term implications and nobody helped in any

way. They helped a bit but would not get really involved. We're told time will tell. You will see in time. But you don't want to wait, do you?

8.4.4 Early intervention

On a more positive note, three parents highlighted that the most valuable advice they received at this time was to have as much early input as possible, and to have it as quickly as possible. Nevertheless, going along with this advice was not always straightforward.

For Mia, Zack and Chloe, therapeutic intervention immediately followed diagnosis, but Jo described how for Emily:

...I had to fight and fight for months to get her a physio. I kept saying that it is not acceptable, you're telling me that the best thing is a physio from a young age, but you did not have one. I was constantly on the phone to the hospital, all the time. I made a real pest of myself, you know I had to, because I just thought she's got to have it.

Mary also recalled the endless wait for Dan to receive regular physiotherapy: 'I had to fight, I have to keep ringing up the office and asking for physio all the time'. Lucy remembered similar frustration and the action taken to resolve it for Lily:

That's really hard because we read other things and it said early intervention is the best and you need help straight away, but nobody would... because they did not know what her condition is going to be and unfortunately we had to go down another route of getting somebody privately to see her because we were wasting time. She was nearly one year old and we didn't want to leave it until she was sort of three and then to be told we could have done something about it.

Sooner or later all the children received some kind of therapeutic input, although for Dan, Lily and Mia, this first meant privately arranged provision for which they had to pay. For Chloe, it only occurred when the family moved to another local authority, specifically so that Chloe could receive more adequate early help of this kind.

Table 8.2 provides a summary of the support the children received, as recounted by their parents. Differentiation is made between support they received early in life, and the support they were receiving at the time of interview.

	Early support	Frequency	Current support	Frequency
Emily	Development group in hospital	Fortnightly 1 hour	Physiotherapy at home	Weekly 1 hour
Dan	Physiotherapy and occupational therapy, both at home	Fortnightly combined 1 hour	Physiotherapy and speech and language therapy in school	Weekly sessions
	Special needs playgroup	Weekly 1 hour	Conductive education	5 hours 3 days a week
	Hydrotherapy	Weekly 1 hour		
	Private conductive education parent-and-child provision	2-hour session twice a week		
Zack	Physiotherapy at home first then in hospital	1 hour fortnightly	Physiotherapy and speech and language therapy, either at home or at nursery	1 hour every fortnight
	Speech and language therapy	1 hour per month	SEYS input from teaching assistant	1 hour input every fortnight
Chloe	Physiotherapy at home	Infrequent, 1 hour sessions, sometimes once every 2 months	Physiotherapy and speech and language therapy, both at school	Weekly 1-hour session
Mia	Physiotherapy in hospital	Weekly 1 hour session	Physiotherapy at home	1 hour weekly
	Private combined development therapy	Weekly 2 hour session	Input from PIMIS	Review visit once a term
Lily	Private combined therapeutic development programme (physiotherapy, occupational therapy, hydrotherapy, Portage)	Block placement twice a year with 6 weeks reviews	Physiotherapy SEYS input	1 hour every fortnight 1 hour every three to four weeks

Table 8.2: Type and frequency of early and current developmental support for target children

The table shows considerable variation in the nature and intensity of early intervention provision for these children. This may be for a number of reasons: differences in complexity and extent of individual needs, in funding possibilities, in

availability of practitioners, and in parents' awareness of what it was possible to obtain. For instance, only Dan and Lily received educationally orientated early intervention at a very early age: conductive education for Dan and Portage work for Lily, both secured through private funding. The other four children were involved only in local-authority funded therapeutic sessions.

Different kinds of health-related input continued for all children throughout their pre-school years. For Zack, Mia and Lily, this remained home-based, for Chloe it became integrated into external childcare and early educational provision. Dan and Emily had a mixture of the two. For those children who had been given a Statement of Special Educational Need at an early age, Emily, Dan and Chloe, there was no involvement from SEYS or PIMIS – they relied on other educational or therapeutic services instead.

8.4.5 Choice of pre-school provision

For all the children apart from Lily, who was under two years old, early therapeutically-oriented input had been superseded by external childcare and early education by the time interviews took place. Such arrangements were heterogeneous – funded or private, mainstream or specialist, full or part-time – and the reasons for the choices made were varied too.

Jo and Steve chose a private nursery with Emily's educational future in mind. This nursery was attached to a local primary school and they envisaged Emily starting there together with other children from the nursery. Progress for Dan in parent-and-child provision at conductive education convinced Mary that he should continue to receive his education there. However, the local authority was only prepared to pay for part-time attendance, resulting in a Dan having a joint placement involving

conductive education and a local-authority special nursery. For Zack, a children centre was recommended by the SEYS team as his most affordable and convenient childcare option. Chloe's admission to the special school's nursery reflected the complexity of her needs and was seen to prepare her for longer-term education at that school. Cath and Neil chose a nursery for Mia because they knew the family of another child with similar difficulties who had attended the school. Mum's perspective seemed to be informed by her own experience as a teacher: '[The school] has already been adapted ... they had some experience of working with a child similar to Mia.'

Emily's Mum, Jo, highlighted the move to nursery as a 'difficult time', although Dad suggested that this separation was more problematic for his wife than for Emily herself. He added: 'Moving to nursery was possibly the best thing which happened to Emily in her life so far.' He was positive about the social change he saw in Emily, a perspective shared by Jo:

Staff [were] brilliant, honestly, I can't say anything negative... I mean K. [Emily's teaching assistant] has been absolutely fantastic. She is really good with her. She knows when to step back and give her her own space. Which is what obviously worries me, with always having somebody there. She doesn't want to have an adult there all the time. No. But K. knows when to do that.

Mary had different reactions to Dan's dual placement at conductive education and the special nursery. In relation to conductive education: 'They have a really good understanding of him. I mean physically they are very aware and they teach him new ways of doing things and he is really doing like what they taught him really.' In the special nursery, however: 'I think they are struggling a little bit...he is in a slightly bigger group now and has a new teacher and she is not as enthusiastic. At set times he goes to the sensory room and swimming, but in between these times he is in his chair really.'

Claire was positive about Zack's attendance at the nursery of the children centre, but in a different way: 'They are just doing play. It's just being a normal child. Then the physio and others go there and Zack receives what he needed in the same place...he just plays up when the physio comes here [his home]... To be honest ... the class teacher is amazing.'

For Lynn, knowledge of and interest in her child amongst professionals was appealing when deciding on Chloe's school:

After visiting many schools, I just fell in love with this one. To be honest, honestly, first I thought J. [head teacher] was one of the car park attendants. She'd got a yellow coat on and she says to me ... she knew what I was, "You are Chloe's Mum, I'll be in in a minute, go and wait in my office".

At the time of interview, Lily's parents were just starting to explore options for her pre-school placement. Nevertheless, they had fairly specific ideas about what this might be. Dad felt that that the best option was their local nursery which Lily's brother already attended and where 'they already had children with special needs, it is all on one level, and the fact that it is local, if help is needed we can pop over'. Mum was more cautious – referring to the forthcoming process for a Statement of Special Educational Needs, she warned: '[It] will detail what I need to go through and how much care she is going to need when she gets to nursery, 'cos at this stage it's still really quite difficult, because she may be walking by then, in another 12 months at least.'

8.4.6 Expectations for development

Interviews also revealed the nature and extent of parents' expectations for their child's development and learning. Without exception they recognized the long-term

impact and influence of their child's cerebral palsy, and in particular the physical, personal, social and emotional difficulties derived from this condition.

They commonly portrayed the process of development and learning as unpredictable. Lynn illustrated this: 'Whatever she does is a bonus...Chloe just surprises you and does it and whatever she does I work with her. But she will only do at her own pace.' Lily's Mum indicated that 'our expectations changed dramatically'; her husband elaborated: 'I mean the first thing when she started to feed. They said she'd never feed. That was the major step which made you think, maybe she will be bad but not as bad as they said.' Cath and Neil shared this evolving process of understanding in relation to Mia's development:

[After diagnosis] we said, didn't we, we need to take this one day at a time...and then it was a case she was smiling and we thought that was positive, and making noises and things like that, we knew she has some understanding. And then it was the mobility really. She is so strong-minded, she does things when she wants to do them. It's nothing what we've done particularly to make her walk. She just wanted to do it one day... We understand now that things take longer we want them to.

Mary also adjusted her expectations as a result of her experiences with Dan: 'I hoped he would progress more, and he has progressed the way I thought he would, but maybe slower than I hoped but he is getting there.' Claire also incorporated her own role in her son's development:

I make him try everything. If Zack is comfortable with himself, he will try and do it more. But just because he is the way he is, I am never going to treat him differently. I am doing many different things with him, I'd love him to walk but I don't think that's ever happen. Just take it day by day.

Finally, Jo and Steve had learned to be guarded about the future. As Dad explained:

We don't think far ahead. That's one thing what cerebral palsy does. You don't. You just can't think ahead. Ideally you hope she is walking, then half of you thinking, God, she is not walking... you just don't know.

8.4.7 Expectations for provision

When parents talked about their children, they also revealed some of their expectations towards the practitioners who worked with them. Emily's Mum, Jo, for instance, made a clear division between educational and health-related input. She regarded arrangements in the nursery as excellent:

The support has been brilliant. If Sally [head of PIMIS] hadn't told me things, I wouldn't know anything, I wouldn't even know what a statement was. I haven't dealt with a child with a Statement before. It was all new to me, but she has sorted it all out and she sorted the nursery support as well.

Jo appreciated in particular the range of ways in which communication with nursery staff took place, for instance in the mornings when dropping off Emily and through parents' evenings and reports: 'I can't believe how much they tell you.' Her husband, Steve, agreed: 'It is not just they tell us everyday what she is up to really, but also telling us lots of good news, things which also ring a bell for us.' Both parents talked in an especially positive way about the work of a particular teaching assistant and about the nursery's contribution to the planning of Emily's move to primary school.

However, they were much less satisfied with the extent of additional input which Emily received, namely physiotherapy and speech and language therapy. They felt that more intense input was needed to improve Emily's independence: 'It concerns me [Mum] because I don't think she is having enough physio as she needs. Everyone is telling me she needs as much as possible at young age and I don't think that is going to happen.' In the view of these parents, increasing Emily's physical and personal independence depended on having more such therapeutic input.

Mary, Dan's Mum, explained her positive feelings towards conductive education in relation to attitudes towards learning, the nature of activity and its outcomes:

As soon as I went in with him, I realized that "oh, we can work with him" and that they have high expectations when playing, moving about, with self-help skills ... Because he is getting more, he loves it.... Although it was a bit stressful sometimes, but it is nice to think that he has been pushed. I think he does needs pushing and now I am noticing he is coming on.

She reinforced this perspective when comparing this provision with Dan's other placement, the special nursery:

The other place does not push him as much and obviously don't do the physical stuff as much... I mean they do a lot of activities, painting and sand and water, they have got the touch screen computer, but I think it is a bit thin at the moment. They keep saying he is grumpy and miserable and doesn't want to do anything, I think because he is in his chair a lot and doesn't get pushed to do enough.

For Claire, Zack's Mum, practitioners' understanding of the capabilities of her son was very important and she had particular concern about the gap between what Zack could do and what others expected him to do. She illustrated this in relation to his speech, claiming that other people did not appreciate what Zack could do: 'He speaks fine. There is nothing wrong with his speech... When he is around other people, he doesn't tend to speak out as much as he does if he is at home.' Claire explained how, for Zack to show his real potential, he needed to feel 'comfortable with himself – if Zack knows something, he will try and do it more, but just because he is the way he is, he should not be treated differently... he just needs more motivation'.

Lynn's expectations of learning support were more practical. She wanted Chloe's basic entitlements met, in particular in relation to what was indicated in her daughter's Statement of Special Educational Needs – a suitable buggy, regular and

reliable transport to nursery, continuity in agreed provision: 'There is a speech and language therapist, but she keeps leaving. They just all keep leaving. That's the thing, they don't stay in the job.' Lynn continued: 'A lady called "S." who is supposed to be in charge of physio at school, I don't even bother to speak to her because the physios are leaving too.' Her perspectives of classroom staff on the other hand were highly positive and similar to Emily's parents' views on communication, detailed above: 'I couldn't have asked for better... they write in her book every day. Sometimes it's what she'd had for lunch, or what she's been doing. Sometimes it's just that she's had a very nice day.'

Mia's parents expressed their expectations towards services by recalling a discussion with local-authority education advisors. In Dad's view, Mia was 'disadvantaged because of her age, and then she is disadvantaged because of her physical disability. So we were saying if she was held back a year [before moving to reception class], she would then be older, so she'd have a bit more confidence, more experience, you know a bit of advantage.' However, he explained: 'I had the impression from literally within five or ten minutes of the meeting, but even before that, the decision has already been made.' Cath explained their reaction: 'I got very upset about it, quite angry... and I still stick to it now, because I think they disadvantaged my daughter's chances of being able to progress through the educational system with a bit of help what she has not been given.' In this case expectations of parents and local authority did not match and the family had to go along with a decision which profoundly disappointed them.

Mia's Dad was critical also about his daughter's education in the mainstream reception class: 'I don't always get the impression that Mia's specific needs are at the forefront of the decisions they make.' Mum expanded: 'They're thinking from an educational point of view, not her physical and emotional.' Dad was even more

critical in his elaboration: 'From just a normal dad looking on it, I think they just want to achieve certain targets, whatever they need to achieve without ruffling feathers and cutting red tape. Mia is just like a bit of a trophy... so they can be seen as an inclusive school.'

On a more practical level Mia's parents shared further expectations, perhaps in part derived from Mum's own experience as a teacher. They wanted Mia to have more developmentally appropriate activities, rather than formal numeracy and literacy tasks. Mum elaborated:

It's not difficult to figure out if she needs a bit more time to get across the playground from one building to another, that should be the same with writing as well. 'Cos it is her co-ordination... Then of course she loses interest, because she cannot keep up, not because she can't do it, but because the expectations are far too high. Try another way.

Dad concluded the topic with concern about the extent to which the school was being realistic in their judgments: '[They] want to back up their decisions. They want us to believe that Mia is achieving things that we know she is not.'

Lastly, Lucy and Mike's expectations about Lily's provision were based on her recent rapid development, which they wanted to be sustained and further advanced. In particular, they were keen to see more input to enhance her communication, self-care and mobility. In their expectations these elements were essential, because:

...she just wants to join in [with other children's activities] and it is just awful for her not being able to. Taking her out anywhere, we're finding it really difficult now, because she wants to be out of her pushchair and joining in and you can't just let her bottom-shuffle around. So walking is the definite focus.

They hoped these expectations could be addressed when Lily's Statement of Special Educational Needs was drawn up.

8.4.8 The future

The interviews also incorporated discussion about the children's futures. Reactions to this final area of discussion varied – some parents were explicit about their hopes and aspirations for their child; others found the topic rather more challenging than talking about more current and concrete experiences.

Jo and Steve's thoughts were focused on Emily's forthcoming transfer to school. Their ambitions and concerns about this event superseded any longer-term desires. The prospect that Emily might or might not learn to walk was part of this immediate concern, particularly for Steve: 'You are too scared to feel optimistic. Because you feel like this just will come back and bite your neck, you will be very disappointed. You just sort of take each day as it comes, I can see she is going in the right direction but she is very slow.' Dan's Mum, Mary, was similarly pragmatic and, as with Jo and Steve, not knowing what the future might hold seemed rather frightening:

Well, obviously I hope physically he is more able, it would be nice just to have his basic self-help skills... but it is so unpredictable and nobody really knows what will happen, so they say "carry on as much as we can with the physio and the other therapies" that he gets ... I suppose I thought of him as a teenager and not more what he'll be doing, no more than the struggle.

Claire, Zack's mother, also had few specific ideas about what the future might hold and seemed to feel instinctively that parenting Zack would in the long term not be an easy task:

I've got no experience, I don't know what to expect. I just want him to be comfortable with himself, I would love him to walk, but I don't think that's ever going to happen... He is mine and I'd rather just be knackered and deal with him myself.

Lynn also anticipated difficulty in relation to Chloe, but more for emotional than for practical reasons: 'I used to cry to myself, I am thinking how I am going to know she's happy if she doesn't smile. It did not bother me the fact that she wouldn't walk or she may not talk, but how would I know she is happy?' In terms of the future, even more than other parents, Lynn had greater uncertainties than concrete ideals.

Cath and Neil's aspirations were closely related to strengths in Mia's character. As Neil explained: 'She is very resilient and quite tough, especially for a girl, like she will fall over ... most of the children would probably cry for a day and she will go "ooo, ooo" ... and carry on.' Mum also believed that it would be Mia's motivation which would drive her progress and achievements, while Lily's Mum similarly highlighted motivation and interest as the main resources which would drive her daughter's future development: 'I think she has started to want to learn things ... you cannot push her, she'll do it when she wants it.' Dad added: 'Yes, she is stubborn now, it might help her as well, she may be quite headstrong, I don't think she will take any nonsense off other children or anything like that.' A sense of fear was perhaps inherent in their thinking about the attitude of others, in particular in relation to Lily's peers, as their daughter progressed to nursery, then to school education.

8.5 Discussion

In spite of the invariably pessimistic prognosis given to them about their child, also described in Landsman (2005), and in spite of – perhaps because of – the early difficulties they experienced with their child's health and growth in early months, parent interviewees tended to develop their own perspectives of their child, independently of professional outlooks. Brotherson and Goldstein (1992), Wolman *et al.* (2002) and Flewitt and Nind (2007) portrayed such parental views as being

dominated by the disability itself, but findings from these interviews concurred more with Read's (2000) and Fisher and Goodley's (2007) studies, which described parents' outlooks as more socially oriented. The most frequently used description of the represented children was that they were 'happy', 'socially interested' or 'confident'. Parents explained children's favourite activities and toys and stressed their interests in aspects of everyday life.

Nevertheless, the parents also showed understanding of the realities of their children's disability, as depicted by Read (2000), McDowell (2010) and Kelly (2010). Evidence suggested frustration at the gap between their child's often pronounced needs and wishes and the limited abilities which restricted their engagement in physical and social environments.

The complex image which parents constructed therefore generally reflected a Vygotskian (1993) view. Although Claire saw her son Zack's cerebral palsy as being purely physical in its manifestation, distancing herself from social implications, other parents incorporated concern at primary implications with anxiety for the child's understanding, confidence, access and interpersonal relationships, seeing these aspects as pre-requisites for successful development in the future.

In general, parents talked little about how their family context might support this development – perhaps they preferred not to share with a researcher what could have been very personal and private experiences. Their outlooks on professional contexts and professional input were more easily expressed.

The earliest professional contact for all six families was with medical environments, associated with health visitors, GPs and consultants. Parents related these contexts largely to investigation, identification and diagnosis of their child's difficulties, as also

described in Landsman (2005) and Fisher and Goodley (2007). Findings indicated distress, almost humiliation, in the descriptions of these interactions by four sets of parents, of a kind also highlighted by these authors. However, this did not link in particular to the medical confirmation of their child's disability itself, as described by Hadadian (1995) and Woolfe *et al.* (2002). In contrast, these parents seemed on balance to welcome such confirmation, and in the two other cases even fought for it. Distress related much more to what they saw as a blunt and degrading prognosis about their child's future and to suggestions about what should be their reaction to their child's difficulties. Expert opinions invariably downgraded the child's potential for meaningful growth and suggested that the parents might adopt this pessimistic outlook also, something which they ultimately and invariably resisted doing.

The almost reverse experience of two parents confirmed Brett (2002) assertion that parental experience with professionals was highly individual and contextual. Their concerns were first ignored or dismissed by one medical professional, then confirmed through diagnosis of cerebral palsy by another. Not only were parents annoyed or confused by this paradox, it may also have contributed to increasing doubts about 'expert' opinion.

The next influential professional context in the lives of children and their parents was less time-limited, more sustained – the therapeutic domain. Input from professionals providing physiotherapy, speech and language therapy or other therapies usually extended from shortly after diagnosis up the time when interviews were carried out, and presumably beyond.

Parents' relationships with these therapeutic contexts were also not without their challenges. This time, however, parental frustration related less to professional attitudes or lack of understanding of professional roles and practices as suggested

by Russell (2003), but more with practical, organizational and operational issues, such as the absence, delay or irregularity of provision, or simply the unavailability of appropriate professionals to deliver it. In one way or other, parents frequently felt let down by the lack of prompt and efficient services. There was a gap between on the one hand what was being recommended and urged by professionals – and what therefore parents came to see as their child's entitlement – and on the other the reality of a shortage of provision. In their perspective, the system seemed to be unable to match its recommendations with input or to address their child's need for professional help.

Four sets of parents wanted and had to fight for more regular, targeted and intense support from these therapeutic services, in ways described by Russell (2011). Physiotherapy and speech and language therapy were high on their agenda in this respect, perhaps accounted for by a lack of other options, or by limited awareness of the possibilities for alternative interventions, as well as the feeling that these therapies could help their child.

The situation for the parents of Dan and Lily was different. In response to what she saw as inadequacies of standard early interventions, Dan's mother sought out conductive education as an alternative provision. Lily's parents secured private Portage work to compensate for what they saw as a lack of input from the local authority. In effect, both parents made use of the voluntary and private options recognized in Government policy statements as elements of the overall early intervention system (Department for Education and Employment, 1997; Department for Education and Skills, 2004b; Department for Education, 2011).

Williams (2011) asserted that parents often perceive such non-maintained services in a more positive light than their statutory counterparts. Indeed, Dan's and Lily's

parents were able and ready to identify the specific benefits of such alternative provisions and appreciated the more positive outlook on their child's disability and the potential which they offered. Moreover, these self-funded provisions enabled them to focus more on their child's development and learning, rather than having to fight for basic entitlements from standard services.

A third microsystem in most parents' accounts was early-years childcare and pre-school settings. All children discussed in the interviews received early educational input of some kind, although for the youngest child, Lily, this involved less regular input from the home-visiting specialist early-years service, based on Portage work, as described by Russell (2007) and others. Parents' selection of such provision tended to be the product of collaboration with educational professionals from the local authority's advisory and support services. For some, this was part of fulfilling obligations in their child's Statement of Special Educational Needs (Department for Education, 2001). The chosen provision commonly reflected not only the child's age and individual needs, but the possibilities for future compulsory education, as described by Flewitt and Nind (2007) and Welchons and McIntyre (2014).

Parents seemed generally satisfied with their arrangements and were more complimentary about them than about earlier medical and therapeutic interventions. Parents saw the early-years settings as appropriate platforms for enhancing their child's social, personal, emotional and cognitive development. However, all except Mary, mother of Dan, saw aspects of physical development as part of additional therapeutic input, rather than integrated within their child's pre-school provision. This perhaps reflected what Rumbold (Department for Education, 1990) and Wolfendale (1997) identified as provision of a range of individual early intervention options, rather than amalgamated services incorporating input for children's all-round development.

Mary, on the other hand, included Dan's physical development and communication in her perspective of her son's conductive-education provision.

Data also conveyed parents' perceptions about the practical, 'hands-on' aspects of helping their children to grow and progress. These involved not only knowing how to do things, but also consideration of the ideal nature of adult-child interaction and interpersonal relationships, as a foundation for children's progression, as expressed in particular by Zack's parents. These central elements of social pedagogy are evident in Vygotsky (1991) and in the work of Sukhomlinsky (in Cockerill, 2009), and in relation to young children's all-encompassing education in Bakonyi and Szabadi (1971) and Millei (2011). They echo views on upbringing rather than simply on education (Kraevskii, 2002; Sukhomlinsky in Cockerill, 2009). Such connections were evident in how parent interviewees viewed the attitudes of the participating professionals, their knowledge and understanding about the child and about cerebral palsy, their professional qualities and their practical capabilities.

Read (2000) argued that there are likely to be differences in professional and parental images constructed about the disabled child. Yet in this study parental views conveyed not simply a culturally and socially influenced picture about their sons or daughters (Russell, 2003) which was different to those of professionals, nor one which only portrayed the child as an individual with particular limitations (Beresford, 1994; Read, 2000). Instead, a more complex picture emerged in which there appeared to be juxtaposition in parental views.

In some respects they wished their child to be treated in similar ways to other children, not to be discriminated against, sometimes not even to have allowances made in respect of their disability. At the same time, however, they wanted them to receive appropriate and adequate input and facilitation to overcome the difficulties

they faced. Such duality of thinking matches conceptualizations of Shakespeare (2006) and Smart (2010) about the inextricable nature of social and physical dimensions of disability experience, reciprocally influencing each other.

The particular approaches and processes which parents identified as being pertinent involved both remediation of physical difficulties by prioritizing physical skills and mobility, as well as nurturing the psychological aspects of development, in particular children's communication and confidence. However, the professional approaches which parents indicated would be helpful to achieve these priorities, such as having close knowledge of their child, having experience of similar children, setting high expectations and using motivation to increase independence, were not specifically related to the child's actual disability. What parents described in these instances were practitioners' understandings and attitudes, those which reflected the basics of good, general nurturing and upbringing and within which the educators' personality, interests, values and power to influence children are imperative features (Sukhomlinsky in Cockerill, 2009).

The evidence which parents gave of the input from professionals did not always correspond with these outlooks, however. While Emily's interaction with her teaching assistant, the attitude of staff towards Dan's learning in conductive education and Chloe's classroom experience reflected these qualities, there seemed to be an absence of such qualities in that accounts of other parents. Moreover, most expected more extended and personalized input than was taking place, more understanding amongst the professionals of their child's capabilities and stronger expectations about what their child might achieve.

Exploration of parents' outlooks involved interrogation of their experiences over time – recollections of earliest times with their child through to current experiences and to

expectations and desires for the future. Parents often made connections between past and current happenings. For instance, they often expressed wish to increase or extend the professional support their child was receiving was similar to their reactions to the deficiencies in such support which they had experienced earlier on. Russell (2003) argued that parents often modify their expectations about their child's future development and learning as they assimilate information from their own experiences and other sources. While elements of medical, social and pedagogical thinking were evident in their perceptions, parents in this study projected overall a sustained, positive attitude towards their child's future learning, in contrast with early experiences and the first prognosis received from specialists.

Such findings to certain degree contrasted with the outcomes of the study by Wolman *et al.* (2001). In that investigation parents were rather pessimistic about their child's future, and in particular for their self-esteem, with physical difficulties hindering independence and communication and the deterioration of capabilities also causing anxiety. Interview results in this study, however, highlighted some positive priorities and aspirations for children's near future at least and most parents had specific and quite detailed plans for pursuing these. They found it more difficult, however, to think in relation to the medium and longer term – nevertheless, this seemed uncertain, rather than wholly negative as suggested by Wolman *et al.*

In these interviews parents' thinking confirmed findings of Brotherson and Goldstein (1992) and recommendations of Russell (2003), according to which parents wanted reassurance that practitioners were fulfilling their roles in meeting their child's needs. This was most prominent in the perspectives of the parents of Emily and of Dan, who had found delays in arranging early intervention even after the child's difficulties had been professionally recognized. Time not being used effectively became itself a concern, therefore. This was evident also when parents expressed anxiety that their

child had not responded to professional input within the defined and limited time allocated for it. More specifically, for Mia's parents, time became the focus of a debate about their daughter's entry to formal schooling. While they felt that additional time in the pre-school setting would be beneficial for their daughter, the educational advisory service considered the child's age as a fixed guideline for transferring her to the reception class. The authority's view governed Mia's progression through the system in this respect.

8.6 Conclusion

Findings once again reflected the four elements of the bio-ecological model. Data relating to 'person' involved deeper scrutiny of parents' images of their child, one related to challenges in development, the other much more socially oriented and focused on personal, social and emotional elements. Examination of 'context' and 'process' revealed a range of outlooks, largely positive in relation to educational settings, rather less so in relation to the extent and reliability of therapeutic provision. The interviews provided extended opportunity to examine aspects of 'time', including anxieties of the continuing provision of professional support and parental determination for their child to succeed. The next chapter examines similar issues in the perspectives of practitioners working with the children of the parent interviewees.

CHAPTER 9: INTERVIEWS WITH PRACTITIONERS

9.1 Introduction

To balance local-authority perspectives discussed in Chapter 7 and parental outlooks in Chapter 8, practitioners' perceptions of their own roles in facilitating children's early development and learning were examined. This chapter reports findings from these interviews.

9.2 Aims

More specifically, this data source aimed to expand earlier understanding derived from the practitioners' survey. Issues arising from the interviews contributed also to interpretation of observed experiences of participating children, to be reported in Chapter 10, and therefore helped again to answer all five research questions.

9.3 Methods

9.3.1 Interviewees

As explained in Chapter 8, the sample for practitioner interviews was synchronized with the sample for parental interviews and the observations, making the sampling strategy purposive. The seven interviewees worked with the six children and families whose situations have been examined in previous chapters. These seven

practitioners represented six different types of early-years provision. All interviewees were female.

9.3.2 Material

Practitioners' views were investigated by examining their role, the strategies they felt they employed to promote participation and developmental progression of the target child with whom they worked, and their views on priorities for this child's development and learning. A full interview schedule is in Appendix F. Questions asked were adapted for individual interviewees, taking into consideration the nature of provision they represented and the job roles they fulfilled.

9.3.3 Procedure

After piloting, interviews were conducted between March and October 2012 in the settings where interviewees worked, with the exception of 'Vicky', who worked at multiple locations and opted to be interviewed in her own home. Once overall consent was gathered from their managers, a preliminary visit to interviewees was made where written and verbal information was shared, consent obtained and logistics of their interview agreed.

A single interview was then carried out with each practitioner, although one interviewee, 'Jenny' from conductive education, had a second in order to explore the nature of her provision more closely. All interviews were voice recorded with interviewees' permission, then transcribed and returned to them for checking. Two made some minor changes as a result, more about grammar than about semantics of the text.

9.3.4 Data analysis

Data analysis followed the same procedures as with previous interviews, as explained in Chapters 7 and 8. The sequence was data reduction, identification of recurring or contrasting issues, and their interrogation as emerging themes against the bio-ecological model.

9.4 Results

9.4.1 Roles

'Helen' was a SENCo, working with Emily in a private nursery; 'Jenny' was a conductor and head of children's services at the provision offering conductive education attended by Dan. 'Faye' was key worker for Zack at the children centre, while 'Sandra' worked as a teacher with Chloe at a special nursery. 'Lesley', a teacher, and 'Tanya', a teaching assistant, were both involved in Mia's mainstream reception class and both volunteered for interview, although separately, not together. Finally, 'Vicky' was a SEYS specialist early-years teacher who worked with Lily and her parents at their home.

The professional qualifications of these practitioners were mixed. Helen and Tanya had NVQ Level 3 childcare qualifications; the other interviewees were trained at degree level. Jenny, Lesley and Vicky had gained Qualified Teacher Status through post-graduate teaching courses; Jenny had undertaken a further four-year training course to become a qualified conductor for teaching children and adults with motor disorders. Faye held a BA (Hons) degree in Early Childhood Studies and defined her role as an 'early-years SEN childcare practitioner'. Interviewees were also at various

stages of their working lives and had different professional expertise. Although all had previous practical experience with children with special educational needs and disabilities, only Jenny, Sandra and Vicky, all employed by specialist provisions, claimed previous experience with children with cerebral palsy. Table 9.1 provides an overview of these characteristics.

Setting	Practitioner	Child	Job role	Qualification	Experience
Private nursery	Helen	Emily	SENCo & key worker	NVQ Level 3	10+ years with children with SEN. Emily was the first child with cerebral palsy Helen had worked with.
Conductive education	Jenny	Dan	Head of Children's Service	PGCert in Primary Education + Qualified Conductor Status	20+ years' experience with children with cerebral palsy
Children centre	Faye	Zack	Key worker	BA (Hons) in Early Childhood Studies	5+ years previous experience with children with SEN.
Special nursery	Sandra	Chloe	Early-years class teacher & key worker	BEd (Hons) in Primary Teaching	5+ years' experience with children with SEND and with cerebral palsy.
Mainstream reception class	Lesley	Mia	Early-years class teacher	PGCert in Ed.	Some limited previous experience with children with SEN. Mia was the first child with cerebral palsy which Lesley had worked with.
	Tanya	Mia	Teaching assistant	NVQ Level 3	Some limited experience with children, but no previous experience with children with SEN. Mia was the first child Tanya had worked with.
SEYS	Vicky	Lily	Specialist early-years teacher & key worker	PGCert in Education	10+ years' experience with children with SEN. Limited experience with children with cerebral palsy.

Table 9.1: Characteristics of practitioner interviewees

Interviewees had different responsibilities within their settings. Jenny, Sandra and Lesley were each involved with a whole group of children – the children in their groups included a child participating in this research. Helen, Faye, Tanya and Vicky were employed to provide support to individual children. Faye, Helen and Vicky had several such children on their workload, including a child participating in this research, but Tanya worked with Mia only.

As shown in Table 9.1, four of the interviewees – Helen, Sandra, Faye and Vicky – were also their child's 'key worker', involving extensive administrative and liaison work with parents and external agencies. Helen explained that her role was 'not simply work with the children in the setting, but also to co-ordinate and follow all the things children need to progress'. Although Jenny did not identify herself as a key worker, she nevertheless talked about having similar professional responsibilities in her position as manager. The other interviewees also reported regular contact with parents, more as part of everyday practice than as a specified element of their role.

All interviewees had pursued additional professional development opportunities. Helen, Faye and Vicky had completed key-worker courses. Helen cited courses on asthma, cerebral palsy and first aid; Faye on multi-agency work, the writing of individual educational plans and SENCo training. Sandra recalled attending only one course – this was about children with profound impairments. Lesley claimed no relevant training and her colleague, Tanya, mentioned only one course – cerebral palsy awareness training. While Helen and Sandra recognized that key-worker and SENCo training had helped them to take on more extended roles, Jenny from conductive education doubted the benefit of courses relating to practical work with children with cerebral palsy:

I felt that people haven't been able to teach me anything [regarding cerebral palsy] that I did not know already. That is not to be arrogant, but it's to say that, the trainer, well, they have very little practical knowledge out there about children with SEN, and about cerebral palsy in particular. When you meet people – classroom assistants, teachers – they really know very little about children with SEN. When they realized that I come from a school and work with children with SEN, they asked lots of questions, so I ended up telling them at the training.

9.4.2 Settings

The professional contexts in which these interviewees worked can be categorized in various ways as presented in Table 9.2:

Practitioner	Provision	Funding	Type	Context	Catchment area
Helen	Nursery	Private	Mainstream	Full and part-time pre-school	Local community
Jenny	Conductive education	Voluntary	Specialist	Sessional, full and part-time provision from 0-18.	Mainly within West Midlands, but also nationally and internationally
Faye	Children centre	Private	Mainstream	Full and part time childcare for children 0-3.	Local authority
Sandra	Nursery unit as part of special school	Maintained	Special	Initially part-time, then full time placement for 3-19.	Predominantly local authority but also from neighbouring authorities
Lesley Tanya	Reception class	Maintained	Mainstream	Part-time nursery, then full-time reception class, leading to school placement.	Local authority
Vicky	SEYS	Maintained	Specialist	Sessional: Home-based for children and setting-based for children 3-5.	Local authority

Table 9.2: Overview of settings and provisions represented by practitioner-interviewees

Helen and Faye worked in the private sector, while Jenny represented a voluntary organization. Sandra came from a conventional special school, while Jenny and Vicky represented more distinct, specialist provision. Helen, Lesley and Tanya were part of mainstream education and only recently became involved with children with

special educational needs and disabilities. Jenny and Vicky worked more than other interviewees with parents; only Vicky worked with child and parents in their home.

9.4.3 Processes for admission

Interviewees described how they or their setting in general received and responded to the children's entry to their provision. Helen recalled Emily's admission to the private nursery: 'Everybody was apprehensive, us, parents and also Emily.' Emily was 'the first child with this kind of difficulty in the nursery'; there was 'parents' reluctance to let her go' and Emily's own 'hesitancy and lack of confidence to do things'. Despite such apprehension, 'everybody [parents and staff] wanted her to come to us and we wanted to make sure we got it right for her'.

In contrast, Zack's admission to the children centre was not such a distinct event. Perhaps due to previous experience, no special arrangements were made: 'We treat [these] children [at admission] as we would the other children. They come with their parents...we show them around ... do a home visit. Families come in to do induction and then we build up the time gradually.' However, Faye, the key worker, pointed out that she needed to rely greatly on the expertise and work of therapists, rather than on centre colleagues, in order to learn how to help Zack: 'I've built up knowledge about Zack by working together with them [therapists], by doing it... then it's just kind of fell into place and it's working well now.'

In the mainstream reception class, Lesley, the teacher, and Tanya, the teaching assistant, both stressed how Mia's earlier admission to the nursery followed the usual procedures for all children. Both suggested that the school's earlier experience with another child with cerebral palsy helped them to foresee Mia's needs. Lesley described this in terms of environmental adaptation: 'We had to make sure that the

physical environment was safe for her... to put in a care room ... to have all the ramps ... carry out a risk assessment for the dining room.' She stressed the role of the PIMIS team, who 'came to see what was needed... before Mia could be taken on safely.' Tanya suggested that her supporting role was to 'make sure Mia accesses everything she can within the foundation stage unit. Making sure she is supported, but also enabling her to be independent.'

Interviewees working in more specialist settings – conductive education, the special nursery and the SEYS team – described more formal assessment of children's needs. For instance, Jenny, head of children services in conductive education, explained at length how Dan would have been assessed:

We look for what a child can do at this present time and how we can help the child to go further... emotional contact, contact with parents, communication, physical skills, movement, mobility, how does the child reach for things, interest, if appropriate for the age, self-care... We are very much looking at an all-round focus... What we like to see is some sort of ability to make a response or contact, however fleeting. It might just be an eye movement which shows that the child has understood and been able to respond some way.

If, as a result of such assessment, it was felt that the child's needs could be met, then most frequently with a young child, 'parent-and-child' services were offered: 'We work with the children, but also help parents to manage their own expectations, with the option of [the child] either continuing in our nursery on a full or part-time basis, which was the scenario for Dan, or continuing with the parent-and-child sessional attendance.' Jenny felt that these processes worked well because 'we have expertise in working with many children who have similar difficulties'.

Sandra, the classroom teacher in the special nursery, similarly explained how Chloe's admission followed usual procedures, making use of recommendations in the Statement of Special Educational Needs, which identified Chloe as having

complex needs. According to Sandra, children started off with part-time attendance in the nursery, before a change to full-time. Chloe's part-time attendance was extended beyond the initial period, however, to accommodate her mother's wish to send her daughter to school for only half a day each day. Sandra also described how integration to the group took place:

We have a meeting beforehand with parents to do a care plan for them, for their medical and care needs. We then assess the care plan side and see how this fits with their daily education, how educational and care fit together. Then we assess this again after a term through observing children and making notes about how things happen in the classroom and with the care obligations.

Vicky also referred to an assessment period in relation to the SEYS home-based services for Lily and her family:

At my initial visit... I would talk about what our service does and inform parents that the provision is voluntary... If they agree, then I do six fortnightly visits ... during which I use a very, very adapted version of the Early Support Developmental Journal. Then we write a report with details on all the areas and we set targets. Then talk it through with parents and decide whether families need regular help, which would be fortnightly, or just monitoring once or twice a term.

9.4.4 Socialization

While discussing the initial stages of admission to services, practitioners invariably focused on a child's social relations – with other children or adults in the setting, or with family members in the case of Lily. They highlighted a range of benefits and social challenges which arose in these milieux.

Participation in peer activity was a key issue for Helen, the SENCo at the private nursery. Emily's 'hesitancy and reluctance to do things' was overcome because 'the

children are all very keen to help her... They all want to sit by her and she wants to sit by them.' It was important to help Emily by 'not treating her differently', and by ensuring that 'she has the chance to do what everyone else is doing... without knocking her confidence'. Similarly, Faye in the children centre recognized how the peer group contributed to Zack's early learning: 'He thrives off the interaction of other children ... and the children are very tuned into Zack. They ask when he's not here, they want to know about him, they ask questions and he interacts with them... They will bring activities and involve him within their play.'

Lesley, the classroom teacher in the reception class, was more specific. Mia was 'a child with very strong will ... who loves storytelling and performing with a vivid imagination'. Activities, for instance story-time, 'give strength to Mia to build relationships within her peer group'. Lesley recognized that in some circumstances this characteristic could become a challenge: 'Mia does a lot of attention seeking and she will scream and bawl if she cannot get what she wants... We had to learn to ignore it and she will calm down and will come to join the group.' Redirecting Mia's attention with the help of the teaching assistant also helped Mia to settle down to group tasks.

Tanya, as the teaching assistant, had a rather more blunt perspective. She felt that Mia needed to learn how to become part of the peer group, because although 'she still does play on her own... she has to learn to be in the class with other children and understand their needs'. Reward strategies and reminders seemed to be how Tanya sought to influence Mia's social interactions and responses.

Sandra, in the special nursery, worked with a much smaller group of children than Helen, Lesley or Tanya. For her, the peer group was not simply a platform for playing and learning, but also a context for social awareness and interaction: 'I'll get

them all together, get them to interact with their friends ... I get them to hold hands so they know they are there, look at each other, recognize each others' names.' She stressed how Chloe 'still prefers adult interaction to playing with toys, she will always look for adults and join with them... We did fight it first, but in fact it works for her, she'll explore, look at things, be more interested when helped by an adult.' Yet this carried its own risks. Sandra was concerned that Chloe was 'quite attached to me, that makes it very difficult actually... She seems more interested in our new adults now which is quite good.'

Vicky, the home-visiting teacher from SEYS, explained social interaction in a family context. She felt able to raise Lily's interest and engagement by involving Lily's mother and older brother. Lily's wish to be socially engaged guided the planning of activities so that social interaction became 'the driving force to move us forward with many other areas of development'.

In the wider context of conductive education the social milieu also appeared to be purposefully used. According to Jenny's narratives, group work was a 'powerful motivator and force for children's development', even with children under the age of one working with their parents. Jenny stressed the role of the conductor in this situation:

The conductor is the one who is leading, who's describing what should be happening, but it is the parent who actually works with the child ... This enables them to go home and to complete the tasks again and again with the child in different situations.

Then when the child gets older and starts to be more independent of parents, 'it is the conductors who become the main educators of the child'.

9.4.5 Physical support

Interviewees described a range of ways in which the children were helped through physical means, as illustrated in Table 9.3.

Interviewee	Child	Adaptation of physical environment	Personalized aids and equipment	Manual help
Helen (private nursery)	Emily	None described	<ul style="list-style-type: none"> • Rollator walking aid • 'Bucket' seat for carpet work • Wheelie stool for practitioners • Pushchair for evacuation purposes • Little basket attached to rollator to carry objects • Springy scissors. 	<ul style="list-style-type: none"> • Moving objects for her from one place to another • Walking hand in hand • Providing support to pull up from floor • Manual help with toileting.
Jenny (conductive education)	Dan	None described	<ul style="list-style-type: none"> • Wheelchair • Augmentative communication aids and switches • Plinths, ladders, stools, grasp bar • Buggy • Adapted cutlery and crockery. 	In most activities
Faye (children centre)	Zack	Tidy indoor and outdoor area to ensure space.	<ul style="list-style-type: none"> • Standing frame • Hydraulic chair • Wheelchair. 	<ul style="list-style-type: none"> • Provided when carrying out exercises prescribed by physiotherapist, sitting on the carpet and using hands • Full support for feeding, changing and transfer of position.
Sandra (special nursery)	Chloe	Disabled-friendly design of building.	<ul style="list-style-type: none"> • Sensory room • Standing frame • Wheelchair • Makaton symbols • Objects with different textures, adapted toys, cutlery, crockery. 	Support with physiotherapy programmes and positioning.
Lesley (reception class) & Tanya (reception class)	Mia	Care room, ramps, special flooring for outdoor play area.	<ul style="list-style-type: none"> • Angled board for writing • Enlarged work sheets • Wheelchair. 	None described
Vicky (SEYS: home-based provision)	Lily	None described	<ul style="list-style-type: none"> • Special table and chair • Angled board for writing • Wheelchair for lunchtime. 	<ul style="list-style-type: none"> • Personal care (dressing and toileting) • Support with walking • Moving about.

Table 9.3 Types of physical support provided for target children

These involved varied adaptations to the physical environment, use of specialist equipment and manual help. Jenny explained the purpose of using specialist equipment, such as ladder frames, plinths, stools and grasp bars, in conductive education: 'It helps the children to sit up straight ... to know where their body is when they lie on it, where their feet are ... It gives sensory feedback about their body, raises awareness of posture and facilitates sitting or moving about more independently.' In relation to their settings, Helen, Lesley and Sandra mentioned more specific 'home-made' equipment, such as a basket on Emily's rollator to bring objects closer to her, enlarged worksheets for Mia and objects with different textures for Chloe. These indicated children's individual problems individually addressed at setting level. Interestingly, apart from Zack's hydraulic chair, no 'hi-tech' or IT-based equipment was identified as being used as physical support with these children.

9.4.6 Pedagogical strategies

Teaching and learning strategies were also described by interviewees. These seemed directed sometimes at the child's difficulty and at other times towards enhancing overall development and learning.

Helen's description of Emily's favourite activity, pretend play, was part of the latter. It enabled adults 'to step right back so she is on her own with the other children, doing whatever the other children are doing'. Vicky also talked about being led by the child's interest in this way – for her child, Lily, this approach was 'motivating and stimulating'. Tanya talked similarly about Mia: 'When we gather her attention, then she does fantastic work.' On the other hand Lesley, the teacher, focused on behaviour management, in which ignoring Mia's 'bad behaviour' appeared to be a key concern.

Faye was most concerned about overcoming Zack's physical difficulties, in particular the need to carry out specific tasks prescribed by his physiotherapist. For instance, when describing his play, she highlighted the need to 'encourage him to use his left hand and then bring things together, passing things across, placing things in containers'.

Sandra from the special nursery and Jenny from conductive education were similarly detailed in their descriptions of pedagogical input. Sandra highlighted how targets covered areas of learning stipulated by the EYFS framework, broken down into very small steps 'so we can see where we are going'. In relation to group work, Sandra explained: 'The most important thing is to individualize everything, because although they come under the umbrella term of having cerebral palsy or multiple difficulties, they are all so different... You can have individualized targets for each child in the lesson.'

Jenny felt that conductive education's approach was also in line with the EYFS framework:

It was not really anything new for us when it came, it was just a new structure on which to hang really... We've always worked in these areas [of learning]... So the way we probably assess things, the way we record things, may have changed, but not what we actually teach or how we teach. It was already there.

Amongst more specific strategies used in this setting for Dan was use of a regular daily routine: 'Every day we have one specific programme which focuses on each area of learning... Although the majority focus on physical development, they incorporate bits of everything.' She also explained how teaching strategies directed towards overcoming a child's difficulties could also encompass an all-round approach to child development – the two were not separate:

So if you want to teach a child to draw, they have to think about where their body is in space, which hand they are going to use to draw, can they keep themselves in an upright position, where is the head, can they grasp onto the crayon, can they hold it for a period of time, can they release it, can they move their hands? All those things are essential. Can they pay attention?... So in a lying or standing programme, it is also teaching them skills to focus on the task, listening skills, cognitive skills and communication.

Jenny again highlighted the role of the conductor in this respect. She described them as 'a leader of the children ... specially trained educators with very good knowledge of both child development as well as cerebral palsy'. This expertise allowed a focus on the child:

We have to work with Dan and what he wants... It is about also knowing what is his facial expression mean, how and when he makes a certain noise, is he unconformable or happy or does he want something... we never look at his various needs in isolation... So at every opportunity during the day the conductors encourage him to do things for himself. Everybody has to remember the things he's been able to do... so it does not just fall to one person.

Jenny explained that the influence also came from other children: 'The group is a powerful motivator and force to determine what and how children doing.' In group activities children's favourite objects and activities were often used, for instance – for Dan – dancing toys, rings and balls.

9.4.7 Collaboration with professionals

Work with other professionals was highlighted by all practitioner interviewees as a noteworthy aspect of everyday practice. However, the extent of such collaboration and perceptions of its benefits were varied.

For Faye, collaboration of this kind was a means by which her own professional and practical proficiencies could be enhanced:

I work closely with all the different therapists who have contact with the child I am supporting... We'll just get in touch and I can say: "Zack's been doing this" and she can suggest things. When she comes in, she'll do her physiotherapy programme and I'll just take it on board and to be fair... now I am quite *au fait* with it all.

Helen, however, was less positive, suggesting that collaboration with external agencies was adversely affected by differences in professional opinion:

I think it is difficult when many professionals are involved... Sometimes I am being told one thing, then another. For instance, I had to draw up a PEP [Personal Evacuation Plan]. The physiotherapist suggested not to use a wheelchair... but the medical inclusion team insisted on using the wheelchair.

The situation had to be solved by common sense: 'We agreed we do what is a) safe and dignified for her, and b) what is good for the one-to-one helper.' The only benefit Helen identified from such collaboration was the opportunity to borrow equipment for Emily to use.

Tanya, Mia's teaching assistant in the mainstream reception class, also focused on the challenges of external collaboration, again finding difficulties arising from differences in opinion:

They didn't quite agree how I did something. Mia went outside with a group of children to do prepositions and they each had a toy, but Mia did not want the toy I gave her. But I felt it wasn't the issue to get her upset about what toy had, because it didn't matter to me, I just wanted her to do the work.

Tanya appeared rather threatened by the prospect of external advice: 'I would say really I've done well to think of strategies to work with Mia myself. I have not had any input from anybody, it is what I thought of myself. I am quite proud of that.' When asked who made decision about Mia's activities, she replied: 'I know different people would agree that the teacher should, but I do mostly.'

There were also varied perspectives amongst those working in the three specialist settings. Vicky from SEYS, speaking from her role as key worker, described a service-based approach: 'We work within TAC [Team Around the Child] that is equivalent to a CAF [Common Assessment Framework] at pre-school level.' In her home-visiting teacher role, she stressed planning rather than practice: 'Often the therapists are the same as we work with other children with. We don't have any difficulties with ringing up and saying, "We need some targets, what should we be working on?"'

Jenny from conductive education was welcoming of other professionals' outlooks and practices:

I had people coming in from the multi-disciplinary team, so I had people from the visually impaired team, from the hearing impairment team, physios, speech and language therapists, and they all told me their input in relation to the children. I gathered everyone's inputs and I then made the decisions on the lessons.

Sandra, in the special nursery, recognized the input from the physiotherapist in relation to Chloe in particular, and explained that during class she followed the therapist's recommendations by using the standing frame and encouraging Chloe to place her hands correctly when crawling.

Jenny highlighted two types of work relating to this kind of collaboration. The first was liaison with other educational establishments, for instance, in the case of Dan, with a Foundation unit of a special school. In Jenny's opinion this shared placement seem to be working well, because 'staff from the other school have been to see what Dan does here ... and they said they try to put into practice some of what they saw here, because they realized that they could do more with him physically than perhaps has been expected'. Jenny emphasized her wish to work with other establishments in this way: 'We want to link up with other provisions, for instance

home-school books go backwards and forwards, use the same IEPs [Individual Education Plans], so we are working on the same sort of things, rather than opposite directions from each other.'

The second kind of collaboration was across different disciplines. Jenny outlined how contact took place with therapists, educational psychologists, social workers and nurses, some employed by parents on a private basis. She felt 'the list is getting broader and broader, with different children coming with more complex needs'. She talked about therapists visiting Dan and other children in conductive education, the purpose being:

...to exchange ideas and to see where we have got things in common and if someone has got something different to offer... And they have taken ideas away from us and we've been able to incorporate their suggestions into our own practice. So it is very much about sharing.

She also cited a recent training course delivered by the specialist visually impaired services, and one on tube feeding and emergency medication by a nurse educator.

9.4.8 Collaboration with parents

Perhaps remarkably, less prominence was evident in interviews about work with parents of the participating children. Apart from the two provisions for children under the age of three – Vicky's work with Lily and her mother and Jenny's earlier involvement with Dan in parent-and-child provision at conductive education – parental involvement appeared to involve exchange of information and discussion of issues, rather than actual joint practical work with the child.

Every interviewee showed regard for parents' concerns, making themselves available either face-to-face or on the telephone to discuss these. For instance,

Lesley, Mia's class teacher, pointed out: 'I am very much aware of the stress Mia's mum is experiencing. She is also a teacher and will discuss everything very openly and honestly... In the mornings when she drops Mia off we share everything really.' Helen talked about 'regular chats' about Emily, at arrival time or going-home time. Faye, Zack's teaching assistant and key worker, discussed forthcoming meetings, usually 'over the phone over lunchtime' or as part of her guiding responsibilities on his journeys to and from the children centre. Sandra, who had no daily contact with Chloe's mother, talked about occasional meetings to sort out transport and attendance, as well as the 'home-school book'.

Similarly, Jenny reported no daily contact with Dan's mother in his current provision, but did describe how workshops and practical hands-on work could engage parents in their child's education:

Each term we focus on something different ... for instance, healthy eating, transferring, outdoor play or self-care skills... Something where parents can come, work with their children in a fun situation and conductors can be giving them advice as they are going along.

Vicky's position was different to other interviewees in that she worked directly with both Lily and her mother. She acknowledged the positive use that Lily's mother made of her suggestions: 'Mum has taken on board everything what we've said and did it and worked on it.' As home-visiting teacher and key worker, Vicky felt it had been imperative to:

...make sure Mum and Dan are enabled, they know what is happening, they know where they are going and they have information and resources to get on and do it. Obviously lots of people are involved with Lily and they all do regular work, but most of the time Lily is with the family. Obviously they have to be prepared for future possibilities ahead of time.

9.4.9 Outlooks on the future

Finally, interviewees revealed their short and medium-term outlooks on the child's development and learning, often discussed in terms of transition to the next stage of education or beyond. In doing so, they showed not only the nature of their understanding of the long-term implications of the child's condition, but also the extent of their confidence in her or his further progress.

Helen was positive about Emily's move to full-time education, but had concerns about less formal times in school: 'In the classroom she will be fine, but she will have challenges with lunchtime and in the playground.' She anticipated difficulties with Emily's mobility, as the independence Emily had already gained would not necessarily be sufficient to meet primary-school demands:

Going down the stairs is awkward, very, very difficult, very, very time consuming and the children are waiting and I think that is the school's main fear. You know when they are all in the corridors and she tries to get down. There are lifts but she does not want to use the lift. She does not want to use the care room either... but I think the school is quite keen to use the care room... She might hold up the children in the toilet area.

In talking about the future, Jenny and Sandra took into consideration the complexity of Dan's and Chloe's long-term needs, which would require a combination of care, education and specialist input. Both thought that current educational arrangements would be appropriate for this longer-term provision, as outlined by Jenny:

I see no reason why Dan would not continue that... His schooling needs to focus on life skills, dressing, transferring, eating skills... although I envisage him needing 24-hour care. So in my opinion, the focus throughout his life will be developing his independence and self-care skills together with communication... Educational will be the least important.

Faye saw Zack's development as just beginning and his current provision as a basis for further progression: 'Building on his current skills, social, physical... Things need to be adapted for him a little bit and still get him involved, but without always making it as obvious.'

As Mia's teaching assistant, Tanya envisaged that that Mia 'will do well with her creativity, but will have difficulties with the workload. She will be good with problem solving, but putting it down on paper will be challenging for her.' Tanya's focus on school learning was shared by Lesley, Mia's teacher, who predicted Mia would do well 'making stories, making junk modeling and talking to children about her creation... That needs to be tapped and used really in her writing as she develops in her literacy.' Finally, Vicky foresaw Lily's long-term education in a mainstream setting and was cautiously hopeful about her prospects:

I haven't got a crystal ball as to how she might do as things get more complex ... but the setting will continually need to make sure that her needs are met. At the moment she is a very outgoing, active little girl who ... demands independence as much as possible and should continue to make progress as I've seen her make progress, phenomenally really. She's not going to the world to pass by, she wants to grab it with both hands. I think she is the type of child who the other children want to be friends with and she will be a benefit in any inclusive classroom.

9.5 Discussion

The seven interviewees represented six different types of early-years provision, each with different arrangements for placement, assessment and practice, each also diverse in terms of educational profile and staff composition. Interviewees' own professional backgrounds and experience were varied too, and they fulfilled differing roles within the settings and in relation to the children who were the focus of the interviews. Such 'ownerships' are perceived as pertinent by Corbett (1996, p34),

since they contribute to the ways in which practitioners construct meanings about matters concerning disability.

Such diversity could have been one reason for differences between interviewees in their perspectives on child-, context- and practice-related issues. Findings in this respect reflected three broad categories: social, individualized (both examined by Oliver, 1996; Barnes, 1997; Goodley, 2001), and a more complex perspective, suggesting overlap and interaction between these two, this duality explained by Hári (1997) and Hári *et al.* (1999).

The socially oriented perspective suggested practitioners' professional focus was on the social well-being and development of children within the provision. Priorities and targets were directed towards strengthening the child's competence relating with peers and adults, as anticipated by principles of EYFS framework (Department for Children, Families and Schools, 2008) and reflecting values of social inclusion (Nutbrown and Clough, 2006). This perspective was evident in particular in the narratives of Helen, who was apprehensive about Emily's interactions with other children in the private nursery, and of Vicky, who described how involving Lily's mother and brother in the sessions was pertinent for her work with Lily. Interestingly, while both Helen and Vicky had extended previous experience with young children in general and with those with special educational needs, Vicky had only limited experience with children with cerebral palsy and Helen had none at all. The social perspective therefore appeared most represented by practitioners in this position.

Results from some other participants suggested a more individualized outlook. In the views of these other practitioners, in particular Tanya, Faye and Lesley, emphasis was placed more on children's individual than on social elements. Central to this outlook was awareness of the child's difficulties derived from their cerebral palsy, in

particular therefore physical difficulties, and recognition of the need for expert, targeted input to remediate these difficulties and bring about change in the child's development. Such understandings mirrored values associated with meeting the diversity of children's needs in the EYFS framework (Department for Children, Families and Schools, 2008), which describes effective early-years practice as coming from 'personalised learning' based on individual targets and support strategies 'tailored...to each child's needs' (p6). These practitioners prioritized work in one-to-one configurations, and showed preference for dyadic adult-child interactive relationships.

While Gindis (2005) rejected the relevance of specialized input that predominantly addresses biological implications of a disability, most other literature recommends incorporation of specialist input, in particular from the therapies, as part of multi-agency cooperation (Tilston and Layton, 2004; Willis, 2009; Farrell, 2011; Westwood, 2013). This approach is considered to be essential for meeting individual needs and specific targets. Tanya, Faye and Lesley similarly argued for the benefit of such collaboration – it helped them to anticipate a child's individual needs at admission to the setting, to make personalized adaptations in the setting environment, and to use or adapt child's personal equipment for everyday activities with greater confidence.

However, data highlighted disadvantages if a balanced collaborative approach shifted to fuller practitioner reliance on the input of therapists and other non-education professionals. First there was a risk of compartmentalizing a child's development into defined areas, so while the educational practitioner remains committed to the child's social, emotional and cognitive development, other aspects are seen as the responsibility of 'experts'. There was some evidence of this, for instance, in Lesley's narratives about Mia's mobility and co-ordination and her use of physiotherapists' advice. Secondly, there is a danger that with little 'expert' input

within the setting itself, a practitioner could assimilate their targets and strategies and seek to replicate their segregated practices in the setting's daily programme of activity, as Faye seemed to be doing in her work with Zack. If excessive, this might alienate the child from peer activities and from the setting's wider social and educational context.

While a reliance on the expertise of other professionals, especially from therapists, was a robust part of this individualized perspective, this could not be said to the same extent to be the case in relation to the children's other principal micro-context, the family. Although practitioners seemed to recognize the family's importance in relation to the child's development and echoed Rumbold's (1990) assertion that parents were the child's first educators, there was little evidence, apart from the sharing information on a regular basis, of the shared values and practices which Nutbrown and Clough (2006) suggested should underpin meaningful collaboration. Overall, the practitioner's role was emphasized, with parents – at least on a practical basis – largely separated from it.

A final perspective on child-, context- and practice-related issues which emerged from interviews intersected with both social and individualized outlooks. This had a more integrated concern, to see the child benefiting in development and learning from appropriate teaching strategies, within his or her peer group, and with due consideration of the implication of his or her disability. This outlook was closest of all the three perspectives to Vygotsky's (1993) perception of upbringing and educating disabled children as a socio-pedagogical process. It also mirrored the view expressed by Shakespeare (2006) and Reindal (2008) that integrating models of disability reflects real-life experience of disability, and that of Llewellyn and Hogan (2010) who saw this approach as better informing educational practice.

This perspective was projected most strongly by Jenny from conductive education and by Sandra from the special nursery. Both reported and emphasized their extended practical experience working with children with cerebral palsy and the importance of this experience for understanding the needs of these children. This recalled Hári *et al.*'s (1999) assertion that effective pedagogical approaches are based on educators' knowledge, understanding and consideration of barriers a child may experience at both personal and environmental levels. Jenny and Sandra, more than the other practitioners, explained in detail their views and experiences through pedagogical dimensions of own practice, such as curriculum, daily routine and directed activity, implying a more purposefully designed framework for organizing children's activities and leading their learning, explained in the literature review as the pedagogical value-system associated with conductive education (Sutton, 1986; Hári *et al.*, 1991; Hári, 1997b; Wilson, 2001).

In the perspectives of these two practitioners, facilitating the children's growth was not simply a matter of adult-child interaction, but a more intricate approach using a range of means, including the children's group, one-to-one support and equipment. For Jenny, for instance, the peer group seemed to be not simply a context for Dan's learning, but also a pedagogical tool to motivate his interactive participation (Baker and Sutton, 2006). For Sandra, working in a group gave opportunity to encourage Chloe to give responses similar to those of other children, adapted according to her level of development, in real social situations. This reflected the notion of collective learning (Shukhomlinsky, in Cockerill, 2009), without which, in the view of Hári and Ákos (1988), activation of children's interest and motivation, activity and independence is difficult to achieve.

Jenny's and Sandra's depictions of the social context within which they worked portrayed practice which was both heterogeneous and homogeneous in nature (Hári

and Ákos, 1988). In their views children were at different levels of development and experienced their difficulties to varied extents. However, they shared developmental characteristics as well, reflected in shared group work and tasks. Moreover, both practitioners agreed on the need to develop children's all-round development, rather than prioritizing one or another. In Jenny's view, helping children to overcome their physical difficulties was essential to enable them to partake in social, self-care and more educationally focused activities. For Sandra, social interaction and communication took priority, but for similar reasons – giving the child influence over activity allowed her or him to become more independent and active in initiating and solving tasks. A sense of practitioner authority in these processes was compensated by seeking to make directed activities interesting, engaging and motivating.

9.6 Conclusion

Discussion of findings from this chapter has focused largely on practitioners' views of the organizational and pedagogical 'processes' which they pursue, including consideration of three types of perspective in this respect: social, individualized, and a more Vygotskian combination of the two. This scrutiny, however, has inevitably brought in two other aspects of the PPCT model: the role of the 'context' in which the interviewed practitioners worked and their perspectives on the child as 'person', in particular in relation to the nature of his or her disability. Data too has covered perspectives of 'time', namely practitioners' views on a child's future development and provision.

Examination of parental and professional perspectives in the data is now complete. A final stage to is to turn to the position of children themselves, evident in their activity in professional contexts. The final chapter on data now turns to these observations.

CHAPTER 10: OBSERVATIONS OF CHILDREN

10.1 Introduction

Results discussed in the previous chapters provided insights from stakeholders representing family, early-years settings and the local authority. Observations, on the other hand, offered opportunity to develop understanding about aspects of children's own everyday learning experiences in professional contexts.

10.2 Aims

The main purpose of this chapter is to report findings from observations of the six target children, each in a different early-years context. This data source was chosen to answer the final research question: 'How is this range of outlooks [from parents, practitioners and local-authority personnel] evident in observed practical interactions between children and practitioners?'

Observations allowed three main objectives to be reached. First, they enabled understanding obtained through interrogation of perspectives in the surveys and interviews to be extended. Secondly, they brought to the fore aspects of professional practice, illuminating characteristics of processes, especially interpersonal relationships, in various types of micro-environments which played a role in children's upbringing. The final objective was more methodological – observations enabled evidence gathered previously to be interrogated, and evidence absent from other sources to be newly identified, in a triangulated fashion.

10.3 Methods

Observations included description of generic characteristics of the context, then capture and recording of how learning activities were communicated to the observed child, how participation was facilitated through interpersonal processes, and what responses were evident within these interactions.

10.3.1 Target children

Target children for observations had already been identified through the samples of parents and practitioners. Table 10.1 provides an extended overview of the demographic background of these children and arrangements for their attendance at particular provisions. As explained in Chapter 5, the sample was created to show maximum variation in terms of such provision, as well as in children's ages.

Child	Age	Ethnicity	Type of setting attended	Attendance
Emily	3 years 11 months	White British	Private nursery	9.15 – 1.15 5 times a week
Dan	4 years 10 months	White British	Conductive education	8.30 – 1.30 3 times a week
Zack	2 years 6 months	White British	Children centre	9.00 – 3.00 5 times a week
Chloe	3 years 10 month	White British	Nursery in special school	9.00 – 3.00 5 times a week
Mia	4 years 11 months	White British	Mainstream reception class	9.00 – 3.15 5 times a week
Lily	1 year 10 months	White British	SEYS home-visiting provision	1 hour session every fortnight

Table 10.1: Information about target children observed

It would have been illustrative to have ethnic diversity also within the sample – however, as discussed earlier, only parents with white British backgrounds

volunteered for the interviews. This therefore determined the nature of sample for observation. Similarly with gender, more parents of girls than boys gave consent to take part in the research.

10.3.2 Material

Each observed session was recorded using the same form, adapted from Sylva *et al.*'s (1980) observation schedule and shown in Appendix G. However, Sylva *et al.*'s time sampling was replaced with activity sampling – this enabled the observer to follow children's tasks or activities through from beginning to end. Use of the form enabled transparency and consistency within and between observations. It was flexible enough to be used in all settings, at different times and with different activities, and to record more complex and longer tasks as well as simpler and shorter activities.

10.3.3 Procedure

Once consent had been given by relevant gatekeepers, a preliminary visit was paid to each setting. This provided a chance to become familiar with the setting's physical environment and routines, with the size and nature of the children's group and with participating adults and their roles. More specifically, it allowed the relationship of these adults to the target child to be gauged and the timing of observations to be discussed. It also gave an opportunity to share with practitioners some detail of the observations and to allow them ask questions about the research. Children were able to become familiar with the face and presence of the researcher.

In most cases observations were conducted in each setting over two days. In the special nursery one whole day was observed and in conductive education observation was undertaken on three separate occasions. This variation enabled saturation of data about each child's overall experience in their setting.

The duration of observations also varied, lasting anything between ten minutes to over an hour, this being dependent on the child's age and the setting's daily routine. Observations were non-participatory, enabling the researcher to capture many dimensions of children's activities and cause as little disruption to the usual routine as possible. Sessions of various kinds were observed – structured and unstructured, adult-led and child-initiated, group and individual – across different parts of these daily routines. Contextual information related to each setting is presented in Table 10.2.

Child	Setting	No. of observed sessions	Total time observed	No. of children/ adults	Adults present	Activities observed
Emily	Private nursery	2	5 hours	21-23/6	Early-years practitioners; nursery manager; area SENCo; TA.	Arrival at nursery; register; free play; structured activities in whole group and in small groups; gardening; snack; toileting; changing.
Dan	Conductive education	3	4 hours 45 mins	5/3-4	2 conductors; TA; trainee conductor.	Register; Group programmes for lying, speech and manipulation, snack; toileting; free play activities; lunch.
Zack	Children centre	1	4 hours 30 mins	19/5-6		Individual and directed play activity; group time: action songs; lunch.
Chloe	Nursery in special school	1	5 hours 15 mins	6/3-4 Child also spent time working 1-to-1	Early-years teacher; TAs; Teacher for visually impaired.	Arrival; group activities while in standing frame; register; pre-maths; art and craft; group interactive games; action songs; drink; soft play area; session with visual teacher; speech tasks; lunch.
Mia	Main-stream reception class	2	5 hours 20 mins	28/4-5	Early-years teacher; 2 TAs each allocated to disabled child; additional class TA.	Arrival; free play; register; early literacy with interactive whiteboard; free-flow play; pre-writing; lunch; early numeracy; small group story time; outdoor play.
Lily	Home-based SEYS input	2	2 hours 10 mins	2/1	Mother; SEYS teacher.	Directed play activities 1:1 with SEYS teacher and with mother.

Table 10.2: Overview of observations

10.3.4 Data analysis

The observation record form included general field notes about the physical environment of each micro-context. These described the number of rooms, their size, layout and other features, arrangements for furniture, equipment, toys and the child's personal equipment, and other features. It was equally useful to capture the social context, for instance the size of the children's group, the number of adults present in the room and how children were organized. The field notes also permitted some generic observations about the children to be recorded for analysis, for instance the means by which they moved about in their settings, their means of communication, and their familiarity with the environment. This strengthened subsequent analysis and understanding of the nature of interactions between child and adults and the relevance or absence of these processes in relation to the observed child's development and learning.

More pertinently, however, the nature of activities was logged, together with the perceived objectives of tasks provided for the observed child. Reciprocal responses between the observed child and others were recorded and the nature of reactions described and analysed. In some activities this involved a single interaction; at other times there was a series of sustained interpersonal, verbal, non-verbal or physical exchanges between adult and child or between the target child and other children in the group.

Data scrutiny therefore began by identifying periods of activity where such interactions between the child and others, predominantly adults, were evident. Issues and ideas derived from the reduced data were analysed, using the same process as with the qualitative interview data.

10.4 Results

10.4.1 Settings

The field notes taken before and during observation allowed 'pen pictures' of each setting to be drawn up. These are summarized below.

a) Private nursery (Emily)

The pre-school nursery is located within the premises of a primary school, but with a fully separate building, outdoor area and entrance. Provision is offered for children from 2.5 years up to school admission. Children have access to one main indoor area and a smaller adjacent conservatory. Outdoors there is a small patio with concrete slabs – here bikes and other outdoor toys are kept. A small garden area, accessible by steps up a steep slope, is also allocated to the nursery.

The main indoor area is usually prepared for different activities – on both observation days tables were prepared for art and craft. In the room there is also a dressing-up area, home corner, building zone, shelves with books and trays of toys at the side. Space looks rather limited; the atmosphere is very busy. Between activities staff often reorganize the room, keeping the environment tidy and often involving children in this. This is also the area where children have their snacks. Washroom facilities are located in the corridor – children usually access toilets in small groups with one member of staff. At the time of observations, Emily was the only child with a disability or special educational needs in the setting.

b) Conductive education (Dan)

The nursery unit for conductive education is located on the first floor of a purpose-built building. Services for younger (parent-and-child) and older (school) children are accommodated in the same premises. The nursery unit is located in one large group room with an adjacent bathroom and an additional small room used for individual or small table-based activities and for staff preparation. A large outdoor area is specially adapted with garden toys, swings, see-saw, gardening area and a large rubber-surfaced patio.

The indoor environment has specialist equipment, wooden slatted plinths, chairs, tables, some of them stationary, others re-arranged according to the session. In one corner there is a carpeted area with a child-sized play kitchen unit. Toys and specialist equipment are stored on shelves around the room.

c) Children centre (Zack)

The observed group caters for children from aged two years; prior to transition to school they move to a different, smaller group. The building is located in a residential area; the observed group is housed in two very large, bright rooms with a well-resourced, easily accessed outdoor area. Each room has stations for different kinds of play activity. The first room has tables and chairs for sitting activities and the 'free-flow' outdoor area opens from this room, making this part of the nursery busy and dynamic. The other room is used for quieter activities, with a defined carpet and cushions area, with bookshelves and a rest corner where about eight to ten children can sleep on mats on the floor.

The outdoor area is very well resourced, with water and sand play areas, space for gardening, bikes, climbing frames, a see-saw, swings and large plastic building blocks. Small kitchen and toileting amenities are located in the corridor of the building; the latter includes changing facilities for younger children and for those with special educational needs and disabilities.

The nursery unit has several children with developmental delay and other difficulties. Each has an allocated support worker for the full length of their time at the children centre.

d) Nursery unit in special school (Chloe)

This nursery unit is located in a recently completed, purpose-built building at a large special school. The school caters for learners aged from two to 19 with various physical, sensory and cognitive impairments and a range of medical conditions. Children are grouped together according to age and the nature of impairments.

The nursery group is positioned in a big, bright room on the ground floor of the building. There is a large space in the middle where group activities are carried out, with children in standing frames or in wheelchairs. Toys and equipment are stored on shelves at the side of the room, together with furniture and children's individual equipment. In one corner there is a large 'soft play' area.

A specially designed outdoor area is accessible from the classroom and has a range of adapted playground equipment, a patio and a gardening area for younger children. Changing and toileting facilities are located in the school. The school also has a variety of special resources, such as hydrotherapy pool, multi-sensory room, a dining

room used by younger children only and activity areas to accommodate development and learning needs of older pupils.

The nursery is led by an early-years teacher, who works with teaching assistants and other specialist teachers, including a teacher for the visually impaired. There is also involvement from a physiotherapist, speech and language therapist and occupational therapist. Ancillary staff deal with children's care needs and class-based teaching assistants support the children during meal times.

e) Reception class in mainstream school (Mia)

The reception class is located as part of the Foundation unit in a separate building of a large, community-based primary school. The unit also accommodates a nursery class for younger children. It has numerous large rooms which open up to each other, so that younger and older children can mix during free-flow play activities. Rooms are furnished with tables and chairs, carpet area, interactive whiteboards and computers, and there are shelves of books and toys at the side. Children share the dining room with primary classes in the main building of the school, but have their own bathrooms and a care room. A very large, defined outdoor area is also allocated to the Foundation unit. This is equipped with climbing frames, see-saw and a 'Wendy house'. It has a large grassed area and specially surfaced play area.

The Foundation unit has several children with special educational needs. As well as Mia, there is another pupil with cerebral palsy in the class. Each has a specifically allocated teaching assistant.

f) Home-based provision (Lily)

Home sessions for Lily take place in a large sitting room at her home, with a French door allowing plenty of light. A small table and chair is placed in front of this door. In the middle of the normal sitting-room furniture there is a medium-sized rug where activities take place. At the side of the room there is a ladder frame which Lily can use for standing and a small table with two little chairs – one chair is adjustable for height and has a adjustable footrest. Various plastic and wooden toys are on the carpet and on the table. Although father was at home, during the two observed sessions it was the mother who worked with her daughter and with the teacher from SEYS.

Sessions with this teacher take place fortnightly. The teacher brings a large bag of specially selected toys to use with Lily – some of these are known to the child, others are new to her. This process also provides opportunity for the specialist teacher to explain to the mother the benefits of particular toys for her child. The teacher also acts as key worker for the family and after sessions with Lily often discusses other issues with the mother.

10.4.2 Children

In spite of having the same medical diagnosis of cerebral palsy, the six children were at very varied levels of development. Emily and Mia were the most independent and advanced in development and learning overall; Zack and Lily showed moderate difficulties; Dan and Chloe appeared to be experiencing complex difficulties in a number of developmental areas. However, for all children the extent to which these difficulties hindered participation in activities only became evident when their activities and interactions were examined.

10.4.3 Interactions

An integrated summary of evidence derived from the observations is presented here for each child. These illustrate issues related to context, also to the nature, extent or absence of interactive responses between the child and adults facilitating them in their activities in typical, everyday scenarios.

a) Emily

Table 10.3 summarizes observations of interactions involving Emily in the private nursery. During both observed days, Emily appeared generally confident, independent, co-operative and engaged in the varied activities of the nursery's daily routine. She responded well to generic verbal stimuli, such as requests to complete tasks, encouragement and reminders. She showed most enjoyment in social, cognitive, self-care and communication aspects of the activities, but appeared less enthusiastic and confident when these also incorporated moving about or fine co-ordination and manipulation. In these instances she still used her own efforts to solve problems, but then often sought or relied on input from her teaching assistant.

The teaching assistant seemed able to recognize the extent of Emily's motivation and the levels of independence of which she was capable, and her input into the child's activities reflected this understanding. She responded to Emily's efforts by praising and commenting on her achievements and maintaining a supervisory role, without helping manually. She also noticed when she needed to distance herself from the activity because Emily was accomplishing the task herself, for instance during snack time or when Emily was playing outdoors.

a) Private nursery: Emily		
<i>Activities</i>	Whole group, structured, adult-led activities, transitions, child-initiated free-flow activities, snack	
<i>Expectations observed</i>	<ul style="list-style-type: none"> • Develop social awareness and interactions • Contribute confidently to group activities • Choose appropriate resources • Engage in activities according to own interest 	
<i>Social context</i>	23 children with 5-6 adults	
<i>Type of activities observed; physical and human resources identified; strategies employed</i>	Transition, moving about	Indoor: 1:1 with TA Outdoor: walking frame + guidance from TA
	Whole-group activities	Specific sitting arrangements for sitting on floor Generic adult supervision
	Free play	Generic supervision from TA Occasional direct help
	Self-care activities	Generic supervision from TA
<i>Nature of responses and interactions</i>	Examples of typical responses during activities	
	Child to task/adult	Adult to child
	Transitions/moving about:	
	<ul style="list-style-type: none"> - Follows instructions, motivated - Determined but slightly hesitant when walking - Demands TA's help - When supported, appears confident and completes task. 	<ul style="list-style-type: none"> - Encourages E to step - Explains what comes next in programme - Offers physical help in form of holding E's hand.
	Whole-group activities on carpet	
	<ul style="list-style-type: none"> - Motivated, engaged, focused on task - Answer questions, interacts, interested, communicative - When loses control over balance or posture, becomes disengaged and struggles to remain focused. 	<ul style="list-style-type: none"> - Interactions as part of the whole group: motivation, questions, modeling, explanations, reminders about activity - No individual response to physical difficulty.
	Free play	
	<ul style="list-style-type: none"> - Selects and moves to preferred play activities - Engages with objects and materials - Observes other children around - Experiences difficulties with more complex and co-ordinated aspects of the activity. 	<ul style="list-style-type: none"> - Encourages, demonstrates - Acknowledges effort, praises, reinforces - Explains, reminds E of what to do - Explains what to do, then provides physical help.
	Snack time	
	<ul style="list-style-type: none"> - Interacts with children, laughs, is engaged - Gets her drink and fruit - Finishes snack independently and tidies up. 	<ul style="list-style-type: none"> - No direct interaction with E.

Table 10.3: Observation of Emily at private nursery: summary of interactions

The practitioner also did not take over Emily's actions while making a picture, despite the fact that the equipment being used was difficult for Emily to handle. Instead she verbally guided her, allowing Emily at least to explore and select materials independently and to use imagination and skills related to her level of development.

However, this kind of interactive encouragement was not always seen when Emily had to deal with more complex demands derived from physical aspects of the activity. For instance, there were several times in the daily routine when she found it difficult to maintain balance on her feet. In these instances she sought help from her teaching assistant, who offered her hand straightaway and set the pace for Emily to move across the room. Conversely, when Emily was taking part in group activity on the carpet, her difficulty maintaining an upright and secure sitting was not recognized by the teaching assistant, or indeed by other adults present. Instead, Emily was reminded to focus on the task, suggesting that her behavior was being interpreted as a loss of concentration. On this occasion Emily was left alone and had to try and deal with her difficulty with sitting herself – she was not able to do so.

Overall, evidence obtained from the five hours of observation suggested that activities were developmentally suitable for Emily and provided generally appropriate challenges for her learning. The nature of interactions and responses between the child and supporting adults indicated an ongoing concern for her emotional well-being, social competence and cognitive development. Most of the time there was emphasis on ensuring that failure which could have arisen from insecure mobility and under-developed co-ordination did not actualize. Emily, therefore, remained generally happy and engaged, although the potential for more independent physical participation and learning seemed unaddressed.

b) Dan

Table 10.4 provides a similar overview of observations in conductive education. During activities Dan showed varied degrees of interest and participation. In some cases he appeared motivated, interested, co-operative and engaged, showing self-determination and perseverance and indicating understanding of and responsiveness

to the tasks. At other times, however, when apparently less motivated, he needed much more extended encouragement and stimuli to remain focused on an activity.

Dan's daily routine in conductive education consisted predominantly of group sessions, where movements in various positions – lying, sitting and standing – were learnt and practised. Expectations of the activity were first shared by a lead conductor with children as a whole group level, then by other conductors to each child individually. Movement activities were done mostly in child-centred ways, for instance through pretend play or by linking movement to action songs. In these activities Dan received one-to-one help. Apart from the free-play session on the carpet, he worked with direct verbal and manual facilitation from the conductor. In the free-play session he had opportunity to move about and occupy himself without direct intervention from adults.

During programmes staff moved around amongst children in the group and appeared to be knowledgeable and confident about when and how to help them in solving the set tasks. Regardless of the nature of activity, these conductors used encouragement, praise and demonstration, both to individuals and to the group as a whole. In relation to Dan, this approach was further emphasized when his level of participation and co-operation seemed low. When manual help was needed, he first received minimum facilitation in the form of a touch or tickle, for instance to lift his head or to attempt steps. This facilitation was then sustained or increased if response was lacking.

Overall, conductors seemed consistent in their expectations that Dan could succeed in his attempts. They invariably encouraged him to increase his control over his own activity and to respond to tasks with greater independence. When he learnt to do

something with help, he was then encouraged to try to do it again more independently.

b) Conductive education: Dan		
Activities	<i>Structured special activities (register, lying, speech and hand tasks); moving about, free-play, snack.</i>	
Expectations observed	<ul style="list-style-type: none"> • Develop social awareness and interactions • Contribute confidently to group activities • Choose appropriate resources • Engage in activities according to own interest 	
Social context	23 children with 5-6 adults	
Type of activities observed; physical and human resources identified; strategies employed	Structured, special activities	Group tasks in lying and sitting positions, D works with 1:1 support Adapted equipment: sided chair, grasp bar on table, footrest, switch for communication. Special objects for tasks: batons, rings, wooden plinth with slots.
	Transitions, moving about	Moves about by pushing wooden ladder in front, receives direct 1:1 support.
	Free play	On carpet, lying on a soft mat. Receives help to choose toy, then generic supervision and verbal support from adults with occasional manual help.
	Self-care (snack)	Sitting arrangements as above. Uses adapted spoon and cup. Participates in eating and drinking with 1:1 support. Two large button-switches for communication.
Nature of responses and interactions	Examples of typical responses during activities	
	Child to task/adult	Adult to child
	Structured, adult-led group activities:	
	<ul style="list-style-type: none"> - Shows initial interest lifts head and visually follows adults - Responds to request by lifting head and initiating movement - Uses hand to press switch to indicate choice - Engaged for short while, then loses interest, whinges, falls asleep - When awakes rejoins the task. 	<ul style="list-style-type: none"> - Sets task for whole group, they sing song about sitting tall - Shares expectations with D - One member of staff allocated to work 1:1 with D - Verbalization of task, group and individual instructions, repetition of task, reminders, encouragement, praise, by group leader and by conductor providing 1:1.
	Free-play activities:	
	<ul style="list-style-type: none"> - Lies on stomach, turns to side - Moves about on his knees, interested, looks around - Moves hand towards selected toy, lifts it up with palm grip, shakes it, bangs it, drops it repetitively. 	<ul style="list-style-type: none"> - Distanced supervision - Verbally encourages, then provides manual help when D's arm is stuck under body - Praises for holding object - Encourages D to use both hands.
	Transitions, moving about:	
	<ul style="list-style-type: none"> - Follows instruction and participates in standing up - Responds to singing, lifts head and stretches arm - Initiates stepping. 	<ul style="list-style-type: none"> - First verbalizes what to do, then helps D manually. Encourages, motivates, reminds D how to keep upright, sings songs to encourage D to step along.
	Snack time	
	<ul style="list-style-type: none"> - Excited, interested, responsive, makes choice by using switch alone - Takes part in holding two-handed cup, pulls it towards mouth. 	<ul style="list-style-type: none"> - Encourages D to make choices for drink - Manually helps D to hold handle of cup - Acknowledges D's attempt, praises, encourages him to do it again.

Table 10.4: Observation of Dan in conductive education: summary of interactions

During these predominately physical tasks, children in the group were encouraged to improve control over their posture, gross and fine movements, balance and co-ordination. Dan was also helped in these tasks by use of equipment: a grasp bar to maintain sitting, a button-switch for communication, a ladder frame to push when stepping, a two-handled cup for drinking. Dan seemed to enjoy using these most when they were accompanied by sensory stimulation, for instance when these objects were adapted so they were shiny or made a noise.

One area which seemed less emphasized in his activities was opportunity for spontaneous social interactions with his peers. Although children's awareness of each other appeared to be an objective of activity, the structured tasks and their completion with adult support when required provided little opportunity for free child-initiated interaction with other children. In some sessions children were positioned in rows so they could see the leading conductor, but this lessened opportunities to take an interest in each other or to observe and copy what others were doing.

c) Zack

Evidence of interactional processes between Zack and his key worker at the children centre is presented in Table 10.5. During the observed activities Zack appeared motivated and co-operative, showing self-determination and persistence to take part in activities made available for him by his key worker, despite his involuntary movements. He understood and followed instructions when the activity was interesting and challenging. He seemed to enjoy being independent and verbalized his actions when engrossed in an activity. He also showed in his behaviour when he became bored or when he found a task too difficult.

c) Children centre: Zack		
<i>Activities</i>	<i>Directed play activity with 1:1 support; lunch; free play.</i>	
<i>Expectations observed</i>	<ul style="list-style-type: none"> • Develop hand skills • Develop communication • Recognize basic objects, colours and people • Develop concentration. 	
<i>Social context</i>	19 children – 6/7 adults; Zack is looked after 1:1 by key worker.	
<i>Type of activities observed; physical and human resources identified, strategies employed</i>	Directed play activity with 1:1 help	Z is positioned in his adjustable wheelchair which is set at the level of his key worker seated in front of him. Z is strapped into his wheelchair at feet, waist and chest height. A large plastic tray is attached to the chair. Ordinary construction toys are used.
	Lunch time	Z is in his wheelchair, pushed to the side of the children's group. His chair is heightened so he looks down on children. Help is provided by key worker standing by Z.
	Free play	Z is taken out from wheelchair and put on carpet.
<i>Nature of responses and interactions</i>	Examples of typical responses during activities	
	Child to task/adult	Adult to child
	Directed play activity in 1:1	
	<ul style="list-style-type: none"> - Excited, interested, starts exploring objects by picking them up, looking at them, sorting them by using one hand - engaged - Verbalizes action - Responds to requests, follows instruction, co-operates - Pushes or drops objects on floor when he becomes bored - Refocuses when objects are changed, watches key worker - Tries to copy action with one hand - unsuccessful - After several attempts, Z loses interest and pushes objects away. 	<ul style="list-style-type: none"> - Offers toys to Z and places them in front of him on tray - Asks Z to pick up and pass on objects of a particular colour. - Acknowledges, praises Z for trying - Offers different kind of activity when Z stops cooperating - Demonstrates how to stick objects together, reminds Z to use both hands - Holds both of Z's hands and sticks the objects together.
	Lunch	
	<ul style="list-style-type: none"> - Excited, hungry, looks at food - Grabs the teaspoon and tries to scoop food, focused on trying to feed himself - Keeps trying hard to scoop food and bring to mouth - Verbalizes: "Eating dinner" - Ignores key worker but eats food placed in his mouth - Pushes key worker's hand away when he has had enough. 	<ul style="list-style-type: none"> - Places food on ordinary plate. A fork and a teaspoon are in front of Z on the tray, talks to Z about the food - Continues to feed Z - Asks Z not to play with food - Acknowledges him eating well, asks whether Z wants more and gives him more food.
	Free play	
	<ul style="list-style-type: none"> - Moves about on his back pushing along with feet, enjoys free movement, vocalizes - Finds large truck and plays with it for a long time. 	<ul style="list-style-type: none"> - Takes Z out of his hydraulic chair and puts him on floor. Asks him to stay on carpet. - Reminds to stay on carpet - No response or communication from adult.

Table 10.5: Observation of Zack at children centre: summary of interactions

Shared activities between the key worker and Dan mostly consisted of playing with objects or looking at books together. Activities were usually decided by the practitioner, rather than resulting from choices made by the child. Interactions were

also initiated by the practitioner, who asked Zack to carry out simple tasks, such as selecting objects according to colour or shape, or pointing to pictures in the book. Zack followed such instructions using one hand until he became bored with the task. When this happened, the adult changed the activity, sometimes to something in which Zack found difficult to be physically involved. The practitioner responded by holding and guiding his hand and explaining the task, but again Zack invariably lost interest within a short period of time and the activity was changed to another one. Similar scenarios indicated that the while key worker responded to Zack when he became disengaged with a particular activity, the first response to this was usually to provide direct physical help, perhaps because she interpreted Zack's behaviour as being the result of physical difficulty, rather than a loss of interest.

An illustration of this mis-match between the child's and adult's intention occurred at lunch time. Zack showed great interest in scooping the food with a spoon and trying to bring it to his mouth, suggesting that he wished to eat his dinner independently. However, the key worker continued to feed him and even asked him not to play with the food. Zack responded by pushing the adult's hand away, but his response was not noticed and control over action remained with the key worker.

Observation also revealed a low level of social interaction between Zack and his peers. While his individualized activities largely matched the group's general activities, he had very little opportunity to interact with other children apart from a short free-play activity on the floor. His position in his wheelchair did not help – its height was adjusted so the key worker could establish eye contact, but this meant that he was seated above other children. Children often passed by and he looked down to follow what they were doing, but his sitting arrangement provided no opportunity to establish contact with them. At lunchtime he was positioned facing the main group of children but away from their table – the concern of adults seemed to

be more that they should have access to help him, rather than that Zack's mealtime should be a social occasion with other children.

d) Chloe

Observations of Chloe took place in the special nursery; summative results are shown in Table 10.6. Field notes suggested that she was settled in the nursery and friendly with other children and staff. On many occasions she initiated contact with others, she responded well to adults' attention and occasionally demanded such attention. During both adult-led and free activities she was active, showing awareness of others and the environment, following adults with her eyes, using her hands, smiling and verbalizing. She was engaged most frequently, however, when one-to-one attention and support from an adult was given.

Chloe's teacher appeared to be both knowledgeable and confident, taking charge of the group's activities and also directing and helping the teaching assistants. The teacher worked predominantly with the whole class, for example setting the task and communicating her expectations to the children, including Chloe. Then while moving around and observing the children's contributions, she asked the assistants to provide particular kinds or levels of support. In this respect the teacher seemed to have clear objectives for Chloe and the other children. She wanted Chloe to do as much as possible independently, but also recognized times when encouragement was not sufficient and more direct help was needed. In these cases the teaching assistant usually provided manual help. The teacher responded positively to Chloe's contributions and extended the task if it appeared too easy. With more complex tasks or when more substantial support was needed the teaching assistant provided support. Chloe enjoyed both group and individual interactions, but appeared to be more responsive when the teacher interacted directly with her.

d) Special nursery: Chloe		
<i>Activities</i>	1:1; whole-group sessions; free play in soft-play area.	
<i>Expectations observed</i>	<ul style="list-style-type: none"> • Develop awareness of self and others • Develop communication • Respond to simple instructions • Use hands functionally. 	
<i>Social context</i>	7 children with 2-4 adults	
<i>Type of activities observed; physical and human resources identified; strategies employed</i>	Directed 1:1 session	C is transferred from buggy to a standing frame with a large wooden tray in front; other children are also in standing frames or in their wheelchairs. C participates in activity with 1:1 help from TA.
	Group activity	C is positioned in standing frame with a large wooden tray in front. Children are positioned in a row facing the board. Teacher in front.
	Free soft play	C is taken out from wheelchair, wears arm splints and is positioned on soft mat. Supervised by visual teacher and physiotherapist. Differently sized soft sponge balls are available for playing.
<i>Nature of responses and interactions</i>	Examples of typical responses during activities	
	Child to task/adult	Adult to child
	Directed 1:1 session	
	<ul style="list-style-type: none"> - Interested, happy, co-operative, follows instructions - Smiles at adults, enjoys interaction, vocalizes - Looks at other children. 	<ul style="list-style-type: none"> - Offers paper shapes of different colours, demonstrates, explains, encourages, motivates, praises, claps - Helps manually - Shares C's success with group.
	Group activity	
	<ul style="list-style-type: none"> - Waits for her turn, engaged, smiles, vocalizes - Follows instructions, responds - Looks around, observes other child. 	<ul style="list-style-type: none"> - Teacher shares group tasks, then communicates to individuals - Explains TA how to help - Motivates, demonstrates, reinforces, explains, gives time, jokes, praises, signs, moves about.
	Free play	
	<ul style="list-style-type: none"> - Moves about on knees, interested in environment, children and adults - Approaches others to gain attention, vocalizes - Engages with toys for a short while, pushes balls around - Bored, unoccupied. 	<ul style="list-style-type: none"> - Supervises but does not interact except when C approaches.

Table 10.6: Observation of Chloe at special nursery: summary of interactions

Encouragement to develop social awareness and interaction was evident in different forms. During register children were asked to say hello to each other – in this instance Chloe clearly turned towards the child next to her and gave a smile. This achievement was shared by the teacher with the whole group of children, suggesting pride and satisfaction as a result.

Opportunity for Chloe to initiate interactions or undertake independent action, however, came about only during free-play activity. Apart from personal care times,

this was the only session when she could move about without the restriction of large specialist equipment, such as her wheelchair or standing frame. When wearing a pair of arm splints and positioned on the mat, her physical abilities became evident. Supporting herself with her hands, she knelt up and moved about on her knees, chasing and pushing a large sponge ball, apparently enjoying a sense of freedom and occupying herself on her own. When she became bored, she approached two adults who were working with two other children and attracted their attention. However, they asked her to wait for her turn to go to the ball area. She looked around, observed a little what the other children doing with the adults, then moved away to find the soft ball again. She soon became bored once more and ended her activity.

e) Mia

An integrated summary of Mia's activity and interactions in the reception class of her mainstream school is presented in Table 10.7. From this, she appears as an active, interested and engaged member of her peer group. During observation she showed ability to participate in all kinds of activities without additional support, until losing interest and motivation. When this occurred, she demanded and relied on help from a teaching assistant.

Mia's activities and tasks were predominantly determined by the teacher and always related to those for the group as a whole. However, how Mia executed these usually depended on her own and the teaching assistant's input. This assistant made herself available to Mia most of the time, but seemed also to recognize occasions when Mia needed to solve problems on her own. In these instances she encouraged Mia from a distance, usually with a smile.

e) Reception class in mainstream school: Mia		
Activities	Structured, adult-led group session; free-flow outdoor play.	
Expectations observed	<ul style="list-style-type: none"> • Develop early maths concepts • Practise use of interactive whiteboard • Improve focus on task • Engage with activity of own interest • Demonstrate appropriate behaviour. 	
Social context	24 children with 2-3 adults; Mia works with an allocated TA	
Type of activities observed; physical and human resources identified; strategies employed	Group session	M works as part of the group with supervision and occasional guidance from her TA. Worksheet is enlarged when required.
	Free-flow outdoor play	Accesses outdoor play area with the TA, walks independently to the climbing frame and plays, with direct supervision and guidance of TA. Wheelchair is located near the building. TA initially provides verbal guidance and supervision, then increasingly gives manual help.
Nature of responses and interactions	Examples of typical responses during activities	
	Child to task/adult	Adult to child
	Whole-class session	
	<ul style="list-style-type: none"> - Arrives at group room interested, chatty. Joins with children's group. - Looks at teacher, attentive to task, engaged, waits for her turn - Motivated, independent, engaged, then make error with task, then tries again. - Smiles and chats generally. 	<ul style="list-style-type: none"> - TA encourages her to join others - Teacher gives guidance on task, explains expectation - Gives opportunity M to complete task in front of group - Praises M for her attempt and explains how to do again - Shares next task at group level.
	Small-group task	
	<ul style="list-style-type: none"> - Moves on her knees to tables with other children - Follows instructions, picks up pencil, tries to write her name - Observes children while waiting - Maintains focus for a short period of time - Responds to direct instructions. 	<ul style="list-style-type: none"> - Teacher sets task to complete worksheet at table - TA provides verbal instructions about what to do - TA takes worksheet to be enlarged - TA encourages M to complete tasks step by step, points to worksheet, reminds, asks questions related to task.
	Free-flow outdoor play	
	<ul style="list-style-type: none"> - Chatty with TA, expresses choice of play, walks independently to climbing frame; lets go of TA's hand and holds onto the climbing frame - Observes other children, initiates conversations - When she becomes insecure, she sits down on the frame, talks to other children - Asks to hold on TA's hand. 	<ul style="list-style-type: none"> - Sustains conversation, gives options what to play with, provides supervision while M is walking - Supervises from distance, explains how to go to top, reminds her to hold on the handle - Encourages M to stand up and to slide down, encourages her to do it independently and to look how other children do it. - Offers to hold M's hand.

Table 10.7: Observation of Mia in reception class of mainstream school: summary of interactions

However, when the assistant noticed Mia was losing focus or experiencing difficulty, for instance because the worksheet was too small to write on or because the task was too complex, she offered more direct support. This was usually in the form of encouragement, reminders, explanations and other mainly verbal stimuli, or by

breaking down the task into smaller, easier segments. On a number of occasions she ignored Mia's protests, indicating that she still wanted Mia to solve her own difficulty without relying on too much help. On the other hand, when Mia's lack of confidence appeared more genuine, such as on the climbing frame, the teaching assistant invariably provided as much direct help as Mia needed and then encouraged her to try again independently.

Overall, Mia's responses to the different tasks and to interactions with adults varied. Praise and encouragement, as well as direct instructions and step-by-step guidance, appeared to improve her approach to problems, and refusals to engage or her complaints about needing more help for the most part ceased when they were ignored. She appeared to benefit from positive reinforcements such as praise at both group and individual levels.

f) Lily

Evidence from observation of the final child, Lily, is presented in Table 10.8. Lily's observations were unlike those described earlier, in that they took place at her home. However, not only was the setting different but the nature of interactions differed also. Instead of being either one-to-one with an adult or a group situation with other children, as in other observations, Lily's activities were three-way, involving Lily, her mother and the visiting practitioner – in Bronfenbrenner's terms a 'triad'. The length of the sessions was shorter – just one hour – from which about 45 minutes was spent with Lily, and the remainder used to discuss Lily's development, in particular her speech, understanding and communication, with her mother.

f) Specialist home-based input: Lily		
<i>Activities</i>	Adult-led play activities, discussion with mother.	
<i>Expectations observed</i>	<ul style="list-style-type: none"> • Develop concentration • Recognize simple objects, shapes and colours • Develop hand-eye co-ordination • Advise Mum on play activities at home. 	
<i>Social context</i>	Lily, mother, specialist early years teacher/key worker	
<i>Type of activities observed; physical and human resources identified; strategies employed</i>	Directed play activities	Sessions take place in living room, on the carpet and sitting at the little table. Primarily teacher is involved with Mia, but there are also direct interactions with Mum. Range of toys used, no specialized equipment.
	Discussion with mother	Mia plays independently nearby, dialogue between the practitioner and teacher.
<i>Nature of responses and interactions</i>	Examples of typical responses during sessions	
	Child to task/adult	Adult to child
	Play activities	
	<ul style="list-style-type: none"> - Recognizes the teacher, waves hand, shows interest in activities, smiles, claps hands - Follows simple instructions - Engaged with both directed and independent play - Smiles to Mum - Offers toys to Mum. 	<ul style="list-style-type: none"> - Greet, asks both Mum and L how things were since last visit - Engages with simple pretend, constructive and role play activities - Encourages M to recognize animals, shapes and colours - Reminds M to use both hands - Explains to M the benefits of each activity - Praises, reinforces, encourages, demonstrates.
	Conversation with mother	
	<ul style="list-style-type: none"> - Shared review of M's progress in areas of speech, understanding, playing. Makes recommendations about how to extend this further. - Discuss process of applying for nursery and getting statement and how to go about getting future speech therapy sessions. 	

Table 10.8: Observation of Lily receiving specialist home-based input: summary of interactions

Lily's activities were mainly determined by the home-visiting teacher. By using demonstration and encouragement and by drawing on Lily's motivation, this teacher facilitated Lily's independent selection and manipulation of objects and afterwards tidying them away. During these activities Lily sustained her interest, was co-operative and enjoyed the sequence of activities. Although these mainly involved just Lily and the teacher, Lily often smiled at her mother, who invariably responded in the same way. While playing with Lily, the teacher occasionally explained to her mother how Lily should be helped – this was often discussed further once the activity was finished.

Overall, the two observed sessions suggested that Lily was attentive and responsive in most activities, showing desire to take control over them. She followed instructions – these were mainly focused on her use of hands, on communication and on solving of problems. Her interactions suggested confidence and this was acknowledged and extended by the teacher's actions and verbal encouragement. Lily's mother showed appreciation of these positive interactions between Lily and her teacher.

As already indicated, the two sessions were partly about helping Lily's development and confidence and partly about helping her mother deal with everyday difficulties, related in particular to Lily's feeding, communication and play. The session observed lent itself to discussion of these issues and this became more in-depth towards the end. The teacher also appeared knowledgeable and concerned about broader issues, such as finding a nursery placement or beginning the process of getting a Statement of Special Educational Needs.

10.5 Discussion

Findings from the six sets of observations provided detailed pictures of each child's interactions in their setting. They largely confirmed Pugh's (2014) concern about diversity in provision and the quality of children's experiences in early-years services. Observed differences in practice related to several elements: use of the physical environment and adapted equipment; the nature of adult help given to children as a result; the overall routines of settings; how group and individual activities were organized within these routines; the nature of adult-child interactions; the wider relationship between children and other children and their activities in their group; and finally the nature of curriculum.

In terms of overall physical characteristics of the settings, many commonalities emerged, perhaps a reflection that the EYFS principle of 'Enabling Environments' (Department for Children, Families and Schools, 2008) was pursued in some common ways. The environment of each setting appeared generally attractive to young children, having toys, furniture, displays and areas for different types of activity, and reflecting the EYFS framework's emphasis on play (Langston, 2014; Pugh, 2014).

In terms of organization and use of space, however, the settings showed much more variation. In the private nursery and in the mainstream reception class resources for play were available all day in different parts of the two rooms used by the children, facilitating free-flow and small-group activities. Langston (2014) considered such conditions to be developmentally appropriate practice, and indeed this may have been the case for the majority of children attending these two settings. However, for the observed target children such organizational arrangements caused difficulties for independent activity.

For instance, in the private nursery Emily either had to wait until the rest of the group had settled down before she could start to move about, or she needed increased help from the practitioner to get from one place to another. Similarly, in the reception class Mia found it challenging to walk with her walking frame because of obstacles in the way – instead, she invariably crawled around the room. In these settings, therefore, contextual hindrances contributed to Emily and Mia's decreased levels of independence and made necessary increased support from practitioners so they could access their physical and social environment.

The physical circumstances of two other provisions, the children centre and conductive education, were rather different. Here the middle of the room was usually

left empty and furniture, equipment and resources were brought into the middle as required for different activities at particular times of the day. This central space was employed flexibly, its use being changed at regular intervals. For Dan and Chloe, this meant that they could reach activities as independently as possible, using their equipment and other facilitation, but without extra help. Distances were less than for Emily and Mia; use of a single room gave Dan and Chloe more opportunities to move and work with normal assistance and for them to gather together with all the other children for social activity.

There were differences too in how equipment in the settings was used. Only the two specialist provisions – conductive education and the special nursery – gave children consistent access to purposefully adapted or differentiated equipment which allowed children to engage in activity and pursue their own wishes. Examples of such equipment included toys of differing size and weight; handles, such as batons, of differing thicknesses; differently sized glue sticks; slanted mirrors; and adapted cutlery.

Consistent use of such adapted equipment was absent in other settings, despite recommendations in the literature that differentiated, personalized devices, in particular mobility and communication aids, are essential to enhance participation of children with cerebral palsy in educational activities (Finnie, 1974; Willis, 2009; Westwood, 2013). For instance, the lack of an enlarged worksheet meant that Mia could not engage in the maths activity until an assistant went to produce one on the photocopier, delaying Mia's engagement; while the high-sensitivity setting on the interactive whiteboard meant she could not display a correct answer, even though she knew what it should be. The use of ordinary construction toys with Zack in the children centre meant that he was unable to manipulate them independently; the lack of adapted art and craft resources in the private nursery meant that Emily struggled

to make her picture. The teacher who worked with Lily in her home also used no adapted resources – for instance, when a simple posting box was used, Lily was able to choose the right hole to post each shape into, but could not drop the shapes through because they were too small for her to hold and release accurately. In these settings, while activities appeared to have been purposefully chosen in relation to the child's age and cognitive and social abilities, the equipment used often did not allow independent completion of the task as it did not take into account the nature of the child's physical disability.

The lack of adaptation of equipment highlights the pertinence of studies by Hemmingsson *et al.* (2009) and Huang *et al.* (2009), which found inconsistent use of differentiated and personalized devices by educators. Evidence from these observations, however, mirrored Hemmingsson *et al.*'s findings, which explained this deficiency in terms of educators' lack of confidence or understanding, more than the reasons given by Huang *et al.*, which involved rejection of use of such equipment, either by the child or by parents.

When equipment prevented the child from completing a task in this way, however, it did not mean there was no response from the assisting adults. On these occasions manual and verbal support from practitioners was invariably increased, compensating for the difficulty. Such behaviour might on the one hand imply practitioners' subscription to Vygotsky's (1987; 1993) notion of a 'zone of proximal development': namely support was adjusted to the child's current level of performance so that a higher level of learning could be assimilated. However, for these children, it seemed they had less opportunity to learn as the activity became increasingly taken over by someone else. The help given served more to compensate for the child's difficulties than to help him or her to learn something new. The children then lost independence – and frequently interest as well – as a result.

The increased facilitation decreased the child's own control over his or her own intent, reversing a shift in power from adult to child over time which, as was seen in Chapter 2, should be in Bronfenbrenner's view an important feature of children's development.

In terms of organization of the activities themselves, Emily's in the private nursery and Mia's in the reception class were generally the same as those for the group as a whole. Their participation in activities, such as register, art and craft, early maths, outdoor play and snack-time, suggested that they were socially aware and engaged: they observed other children and initiated and to certain degree sustained interpersonal interactions with them, mainly in small-group scenarios. However, there was little differentiation in how they performed these activities, except in the extent of manual help given, and in general this was given in response to difficulties which became evident during the activity.

In contrast, there was substantial differentiation for Dan in conductive education and for Chloe in the special nursery when working with their peer groups. This was evident in individualized use of equipment and in the type of one-to-one support given to them to accomplish tasks set for the group as a whole. This support seemed more often anticipated, part of thought-out ways for helping the children to engage in activity equally with other children, rather than being provided in response to difficulties seen by practitioners during the activity itself. This was a reminder of Hári's (1997a) assertion that one of the conditions for successful education of a child with cerebral palsy is purposeful anticipation of both personal and environmental barriers which the child may experience. In addition, when the focus of the leading and facilitating adults was more on the process of the child's learning than on the outcome of the activity, as was the case in these settings, it triggered the use of

wider spectrum of facilitative strategies – verbal, social, manual and environmental, rather than just on verbal and manual help, which was the case elsewhere.

In terms of pedagogical strategies which practitioners in the two specialist settings used to accomplish such differentiation, however, differences between practice in these two special settings were evident. Dan's programme echoed collective learning (Shukhomlinsky, in Cockerill, 2009). In spite of his individual needs he consistently remained part of the peer group's programme of activity. Conductors' actions, for example their communications with the children, their feedback and demonstrations to the group and to individuals, and the facilitations given to children so they could accomplish tasks together, mirrored Hári's (1997a) further assertion about meaningful practice being delivered by adults who have skills to co-ordinate both the activity of the whole group and the contribution of each child to this group work, as well as the ability to use observations to recognize when goals, expectations and circumstances need to be altered in light of an individual child's actual performance. Group work in conductive education was adult-led in formal learning situations, but conductors were also attentive to the children in more social scenarios, such as meal times or free play. Here conductors did not take lead roles, but provided help, often minimal, for children to become interested in the group's activity and take their own active and independent parts in it.

On the other hand, while Chloe's activities also took place in a group of children, the strategies by which collective work was sustained in that setting were different, representing more the ideas of personalized learning depicted in the EYFS framework (Department for Education and Skills, 2007). During the majority of time observed, Chloe accomplished all set tasks with one-to-one guidance and support from a practitioner or teaching assistant. As a result her tasks involved almost exclusively a dyadic adult-child, rather than a collective approach.

Zack's social experiences in the children centre were much more limited than those of the other observed children. In terms of use of the environment, discussed above, Zack had one, very large space, within which he was moved in his wheelchair by practitioners. The problem was not so much with his mobility, but more that he was separated from other children for nearly all activities. Regardless of the nature of activity, he only had opportunity to relate to his key worker, being physically away from the activities of the rest of his peer group, even while playing or having lunch. Social interactions were restricted throughout his day to those with adults, despite Zack's apparent interest and curiosity about what other children were doing and indications that he wished to interact with them. In this case there was little evidence of understanding and use by practitioners of developmental influences derived from children's interactive experiences with peers. According to Hári and Ákos (1988) these influences activate children's interest, motivation, activity and independence; according to Sutton (1986) and Sukhomlinsky, in Cockerill (2009) they enhance the development of higher-level psychological and personal attributes.

There was variety too in the nature of the routines which the children followed in their settings. For Lily and Zack there was little pre-determined programme, the flow of activity being largely determined by the level of interest and engagement they showed. If they were unengaged, the activity tended to be changed; if engaged it was continued. In contrast, Emily in the private nursery and Mia in the mainstream reception class needed to fit in with the general, undifferentiated routine of the group as a whole. The two specialized settings, conductive education and the special nursery, had more complicated arrangements – both had a structured daily schedule in which general activities were undertaken by all, but differentiated in accordance with the children's perceived needs. The structure had some flexibility too, for instance a task might be repeated or omitted if seen to be appropriate by the practitioners.

The type of interactions in which the children were habitually engaged within these routines also showed differences. Between Zack and his key worker there were sustained and clearly defined dyadic interactions. Lily was part of a triad: herself, her mother and the practitioner, with the last taking the lead role in the sessions. Emily, Chloe and Mia also interacted in a triangulated fashion, with the teacher or practitioner in charge and with the teaching assistant who had sustained contact with that child. Dan too worked in a triadic system, but in contrast the adults within these triads changed – the lead person and the facilitators were not always the same, even exchanging roles on occasions.

The characteristics of these different adult-child interactions cast light on the pedagogical strategies which practitioners used to enhance them. In all settings practitioners extensively employed means of verbal facilitation when helping children: instructions, encouragements, reminders, explanations of tasks. In the non-specialized settings, however, the activities and achievements of the target children were largely an individual matter, not perceived by or communicated to the group as a whole, whereas in the two specialist settings the sharing of tasks and of success with the group was frequently evident. This latter approach reflected perspectives of Hári and Ákos (1988) and Baker and Sutton (2006) that use of the children's group as a whole for social motivation can be one of the most influential pedagogical platforms for children with cerebral palsy.

In both these specialized settings, social awareness, interaction and communication between the target children and others were encouraged through adult-led activities. However, in conductive education expectations showed a more holistic orientation, a wish to enhance children's all-round development, including physical growth, independence and their desire to do things. In the special nursery the curriculum was

rather more selective, with an emphasis on mainly cognitive aspects of Chloe's development.

10.6 Conclusion

The nature of children's learning experiences, manifested in the observation data, represented a range of factors related to elements of the bio-ecological model. The extent of environmental adaptation: room design, use of space and adaptation of furniture and equipment, was in the main a reflection of 'context'. However, these aspects reflected also the nature of 'process' – how things were done, being part of the facilitative strategies employed by practitioners to encourage or guide the child's completion of tasks. Other strategies included varied use of verbal encouragement or direction and of facilitation from the group. Both context and process linked to practitioners' perceptions of the needs and abilities of the young disabled child, the 'person', with cerebral palsy. Interactional configurations, the basis for the strategies by which children's participation in activity was facilitated, were also evidence of process, taking different forms: dyadic and triadic in relation to adults, and multi-person when other children were involved.

This scrutiny of observations concludes the reporting of findings from the six data sources. The study now progresses to its final chapter, in which results from all these sources are drawn together, related to ideas in the literature and used to address the research questions in an integrated, comprehensive and analytical way.

CHAPTER 11: DISCUSSION AND CONCLUSION

11.1 Introduction

This combined-method, exploratory case study focused on stakeholders' perspectives about supporting the development and learning of young children with cerebral palsy and on evidence of such outlooks within children's educational experiences. The investigation was conducted within a local authority in the West Midlands of England; analysis of findings was framed in relation to Bronfenbrenner's (1995) PPCT model.

This final chapter returns first to each of the five research questions, debating findings of the empirical chapters and drawing on ideas raised in the literature review. Notions of pedagogy and upbringing are then revisited to elucidate implications for discourse and practice. Within a review of the study's design, the efficacy and practicality of applying Bronfenbrenner's model is considered, together with reflection on the researcher's own role in this investigation. Finally, the chapter considers the wider implications of the study's outcomes for future research.

11.2 Research questions

Five research questions were set for this investigation:

RQ1: How is the identity of young children with cerebral palsy in relation to their development and learning perceived by their parents, early-years practitioners and representatives of local-authority support services?

RQ2: How are the contexts in which support for their development and learning takes place viewed by these stakeholders?

RQ3: What are these stakeholders' perceptions of the processes by which development and learning of these children takes place?

RQ4: In relation to time, how are future priorities and possibilities for the development and learning of these children viewed by these stakeholders?

RQ5: How is this range of outlooks evident in observed practical interactions between children and practitioners?

As shown in Table 2.1 in Chapter 2, research questions 1 to 4 mirror each of the constituent elements of Bronfenbrenner's PPCT model. As elsewhere in this study, the order in which these are addressed in this chapter is slightly different to this abbreviation, with scrutiny of context made before examination of process. This is so that understanding of settings can be gained before understanding of what happens within those settings is sought. The fifth question is different, taking the study beyond the formal framework and examining children's observed experiences in order to critique and extend considerations gained from analysis of the four elements of the model.

Reporting evidence within the Bronfenbrenner-based categories proved challenging in the study. Findings thought to be relevant for one research question were found also to affect and involve discussion of other questions too. This reflected the 'interconnections' which Bronfenbrenner (1979, p8) himself identified between these elements. Even within the model itself, the levels of 'context', illustrated in his image

of concentric circles surrounding the child described in Chapter 2, were difficult to handle in a systematic way. Nevertheless, this inter-relatedness between and within the four categories ultimately intensified the analysis and strengthened the outcomes reached. The chapter now examines each research question in turn, discussing the integrated evidence which emerged from the various data sources.

11.3 How is the identity of young children with cerebral palsy in relation to their development and learning perceived by their parents, early-years practitioners and representatives of local-authority support services?

This first research question sought to understand stakeholders' perspectives on the developing young child with cerebral palsy. In doing so, it positioned these children at the forefront of the study.

The literature review highlighted a spectrum of orientations on their perceived identity: medical and focused on the individual child's difficulties, for instance in Cogher *et al.* (1992) and Hinchcliffe (2007); social, being most concerned with the child's relationship with others and the physical environment, explained by Parkes *et al.* (2001) and Fox (2003); and socio-pedagogical, focused on how these children develop and learn within social settings and most strongly evident in Sutton (1986), Ákos and Ákos (1991) and Hári (1997a). Findings confirmed the actuality of all these perspectives within the views of groups taking part in the research. That is not to say that such outlooks existed singly in the thinking of any particular group, or even that they simply co-existed one with another in the data. Rather they were seen to evolve, alter and intertwine with each other, reflecting particular times or circumstances or appearing as a reaction to particular influences or events.

In relation to parental outlooks in particular, each of the three perspectives was evident. For most – but not all – parents, the early stages of their child's life were most clearly associated with medicalized, individual perspectives, when they were informed about their child's brain damage and consequent severe and complex disability. This deficit-oriented identity, so strong in the historical medicalization of the impairment of cerebral palsy recounted in the literature review, was not asked for by these parents, but rather was forced on them by the information they were given about their newborn child. In this perspective the infant is a vulnerable, dependent person, in increased need of parental and professional support, although the idea that such support might bring about substantial development appears often in doubt. In the recollections of these parents, the negative outlooks associated with this often blunt perspective seemed to downgrade not only their child, but also their own potential as parents to alter their child's prospects.

Social perspectives, associated in the literature review with changing perceptions of disability in general (Oliver, 1996; Swain and French, 2000), seemed for these parents to appear later, when they became interested in and apprehensive about how their child might be regarded by society and how he or she might fit in with activities and society's norms (Goodley, 2001; Thomas and Loxley, 2007). This could partly have been a reaction to the pessimistic nature of earlier medicalized views, perhaps too a result of the child's developmental progress, which for most, although slow, limited and difficult, started to prove such overtly pessimistic outlooks to be incorrect.

The growth of more social perspectives did not mean, however, that health-related perceptions disappeared. Indeed, in the survey, parents continued to see how their child's development was being severely affected by her or his neurological condition and the difficulties this caused. Physical skills – mobility in particular, communication

and self-help skills were particular concerns in this respect, reflecting parents' dualistic orientations – social and medical – when considering and describing their disabled child.

Some other parents had a different experience. For these, it was not medicalized perspectives which dominated the first days and weeks of their child's life, as there was no diagnosis, no negative prognosis, no real professional recognition that something was 'wrong'. For these parents, therefore, hands-on, practical experience of parenting was the earliest influence impacting their image of their child. They remembered early distress about their son's or daughter's generic health, the difficulties they had with feeding, and their apprehension about interacting with their child in other ways. In this respect the early identify of the child was much more socially oriented. They themselves then had to seek out – almost campaign for – a medical perspective which would explain their child's difficulty as well as justify their personal concerns.

In both cases, whether a medicalized or social outlook was the first perspective created, the growing attachment between young child and parents, reflecting Bowlby's and Ainsworth's seminal ideas, played the greatest part in eventually defining their child in their eyes and minds as a social more than as a disabled person, as a contribution to the family, rather than a burden to it. This entailed securing not just a static conception of their child's identity, but a more affirmative, progressive 'learning' image in which the child's medical, deficit-oriented identity was balanced with an alternative perspective in which the child is seen as having potential for development of some kind and which could encompass more positive hopes and aspirations for the future.

This identity, as described in Ákos and Ákos (1991), grows from regular parent-infant

interactions, not simply affirming the child within a social mindset, but also reaffirming the parents' own roles in supporting and helping their child to grow in the real world. It also illustrates the Vygotskian inspiration in Bronfenbrenner's idea that development involves mutual, two-way processes. The child's attributes influence parents' outlooks and parents steer the course of their child's development. Crucially too, it also reflects the third outlook, the socio-pedagogical perspective, which conceives child development as being the product of dialectical interactions. In this respect the identity of the young child with cerebral palsy is intertwined in the growing identity of others, in particular those closest to him or to her.

This leads to the question whether the balance between different images, including this socio-pedagogical orientation, is evident in the perspectives of others also, those in more distanced positions from the child and who have professional rather than parental responsibilities. The survey and interviews with practitioners indicated a varied range of outlooks in this respect. Not surprisingly, medically oriented views were prominent, resonating with the majority of understandings available in the broader professional literature on supporting children with cerebral palsy, such as Fox (2003) and Farrell (2008). Perhaps reflecting the recent widespread emphasis on inclusion, there was also a strong tendency to embrace social considerations, the kind put forward by Nutbrown and Clough (2006) and evident in curricular principles embedded in the standards and learning requirements of the EYFS curricular framework. Practitioners expressing such views indicated less concern, however, for other aspects of the children's development, most notably physical elements and aspects of self-care.

This prioritizing of one area of development over another represents a possible response to Norwich's (2008) 'dilemmas of difference', whereby stakeholders take the option, for the purpose of 'including' the child, not to focus on his or her difficulties

derived from the disability, but to address the more generalized areas of development which are applicable for all children. For practitioners in general, one can appreciate that this kind of dilemma might create a degree of nervousness about how to describe a child with cerebral palsy from a 'strengths' as well as a 'difficulties' point of view. Some, indeed, viewed the development and learning of children more from the 'difficulties', more specifically from a 'motor difficulties', perspective. In doing so, they relied substantially on therapists' understanding and practical advice to inform their support for these children, thereby replacing educational expectations and objectives with those relating to contexts and practices of a different profession.

A third kind of identity given to the child – again not singularly medical or social – was evident in the thinking of two practitioners, both working in specialist settings. Their views resonated more with Vygotsky's (1993) conceptualization of a disabled child's psychological development as a qualitatively different process to that of other children. Interestingly too, both of these practitioners explained the developmental characteristics of the children more from a pedagogical point of view, focusing holistically on the implications of cerebral palsy for children's all-round development, similar to the 'learning' image seen in parents' perceptions noted above. For these practitioners, development was not just about progress in skills and performance, but more essentially about addressing children's psychological difficulties with learning, those relating, for instance, to interest, motivation and aspiration. In this process, purposeful, goal-oriented social interactions with practitioners and other children were seen as central influences. These views echoed Sutton's (2008) depiction of cerebral palsy, cited earlier, as a 'disorder of development', requiring in the Vygotskian perspective pedagogical consideration of both primary biological and higher levels of psychological difficulties for development and learning.

A third set of research participants, those managing the local-authority's three

support services, conveyed rather more blurred perspectives on the development and learning identities of children with cerebral palsy than other groups. Located professionally between micro and macrosystems of professional activity, they perhaps found themselves entwined in addressing both national expectations in policy set by obligatory directives as well as demands coming from families, early childcare and educational settings and other professionals. In reflection of national norms for a multi-agency framework and expectations to be family-centred in outlook, they were also seeking to work procedurally with others, using a discourse described in both independent (SEN Policy Group, 2009) and current official literature (Department for Education, 2011) as reflecting an outdated and overly bureaucratic special educational needs system. This situation may not have encouraged these local-authority personnel to think beyond the broad and generic categories of children's difficulties and needs towards more specific perspectives, underpinned with pedagogical values and related to particular groups of children, such as those with cerebral palsy. Instead, they seemed somewhat routinely to apply a common, 'umbrella' identity to all children with whom they had contact, reflected in generalized managerial thinking and procedure.

In summary, the assimilation of divergent perspectives amongst stakeholder groups corresponded with the idea of Shakespeare (2006), who argued that any attempts to project a single identity for a disabled person are in one way or other incomplete. However, findings also suggest that this assertion is still somewhat unfinished. Emerging from this discussion is the idea that at an empirical level different outlooks behave interactively and even dialectically, producing more complicated, combined, compromised, but operationally acceptable ways of thinking, parenting and working. At a more theoretical level this dynamic process seems to verify Vygotsky's (1993) conceptualization of disability, and within that perceptions of children with cerebral

palsy, as a situational, socially and culturally determined and perceived phenomenon.

11.4 How are the contexts in which support for development and learning of these children takes place viewed by these stakeholders?

The second research question examined stakeholders' views on the roles which different social and professional environments were perceived to play in the overall support system for young children with cerebral palsy. The focus of discussion here is the second constituent element of Bronfenbrenner's model: 'context'.

The literature review included Carpenter's (1994) assertion that in order to meet the diverse needs of disabled children and their families, there needs to be a dynamic early-intervention system that can accommodate a variety of demands. In terms of range and type, parent respondents to the survey – 15 years after Carpenter expressed this ideal – indicated no shortage of provision. Indeed, the 50 children represented in the survey received professional support from 20 different services. A similar picture was obtained from the practitioner survey – its 85 respondents were affiliated with 13 different services. Most of these were associated with reception classes and nursery units in maintained mainstream primary schools, children centres and other pre-school settings, reflecting the national move towards more inclusive early-years services described in Chapter 3. Others were working in the voluntary or private sector, illustrating the pertinent role played by non-maintained services in supporting disabled children and their families (Miller, 2000; Ekin, 2012).

There could be several reasons for this range and variety. One is the priority given in recent years by government policy to increasing the availability of early-years

services for disabled children and their families (Department for Education and Skills, 2004; 2007; Department for Education, 2010; 2011; 2012). It can also be seen as the consequence of historically separated provision for care and education within a rather incoherent early-years system, described in Rumbold's (1990) report, a system now composed of a much larger number of different services but still lacking in overall organizational integration.

A third possibility relates to the idea that early-years arrangements overall are 'patchwork' in nature, as described by Bertman and Pascal (2002) and Wolfendale and Robinson (2006), and acts as a reminder of Pugh's (2014) important assertion that diversity in provision threatens its quality. Pugh (2014), together with Tickell (2011), Hadfield and Joplin (2012) and others, has highlighted also a demographically rather complex workforce with diverse backgrounds, qualifications and experience, which potentially has similar effects. The findings of this investigation provide further evidence of these two features of the contextual system – the target local authority was, it seems, little different from others elsewhere in this respect. The study at one stage also indicated a third mixed feature: the patchwork nature of responsibilities held by practitioners working within the system itself. One might assume that this feature too bears similarities to other local-authority situations elsewhere.

The sections which follow examine evidence emerging about the main types of context researched in the study. Findings from all sources are integrated in order to do this.

11.4.1 Family context

In the parental survey, the family microsystem – for Bronfenbrenner the most immediate and influential context for the growing child – was almost wholly represented by mothers. The inclusion of three fathers in the six parent interviews was a welcome opportunity to collect wider perspectives. Regardless of gender, however, interviewed parents were strongly concerned that their child's development and learning needs should be met promptly and adequately. In interviews, the parents, particularly the six mothers, were conscious of the kind of intensified practical work and additional responsibilities which are required when bringing up a disabled child, emphasized by studies by Pianta *et al.* (1999) and Read (2000). They showed no reluctance to attune to the kind of day-to-day care of a disabled infant described by Pelchat and Lefebvre (2004). In fact, mothers and fathers conveyed a great deal of further commitment and perseverance in seeking what they believed to be the best for their child. In this way, parents seemed to be acting not just as carers of their children, not even just as 'advocates' and 'negotiators' for them, but invariably as 'fighters' too. This situation is reminiscent of Read's (2000) conclusions about families of children with other disabilities in her study.

The realities of bringing up a disabled child described by the interviewed parents, including the role played in nurturing her or his progression, showed some similarities to the processes of upbringing of any child. However, many tasks which had to be undertaken were qualitatively and quantitatively different to those faced in more ordinary circumstances. Most of these altered or additional responsibilities were associated with helping their child with posture, movement and self-care, as well as dealing with health difficulties beyond those normally encountered by young children.

Importantly too, parents had significant responsibility for pursuing and showing their own commitment to different types of early intervention services. In this respect they habitually appreciated and admired practitioners and other developmental contexts with similar outlooks to themselves, namely having positive attitudes which valued the social, individual, and 'learning' identities of their child. This may have reflected a desire for their own generally affirmative outlooks to be validated, or for their advocacy role to be matched by similar actions of others. In the interviews the impression was also gained that approving the work of positively oriented professionals allowed parents to further reject and distance themselves from the negative outlooks with which most had been presented in medical contexts in the first days of their infant's life.

Interviews with personnel from the local-authority support services suggested positive perspectives of this kind at management level too, with general recognition of this role of parents as children's first educators, as advocated in the Rumbold (1990) report, and of the family context as the child's primary context for development. The family context was also considered to be the optimum for non-parental specialist support, at least in the first one or two years of the child's life. Nevertheless, parental and professional interest or opinion did not always match, causing tensions to arise. This occurred most frequently when medium and longer-term educational placements were being considered.

11.4.2 Portage

Portage work and other kinds of home-based support are seen to stimulate the child's overall early development and learning through practitioners' interactions with the child and parent, and in this way to empower parents to engage more meaningfully with their developing child (National Portage Association, 2014). Many

children represented in the parental survey were receiving this input and most parent-respondents confirmed the benefits of the approach for the child and for themselves.

In contextual terms, Portage work is a bridge between the family setting and external settings, such as nursery or school. In terms of process, it initiates both child and family into educationally oriented input, interfering with the dyadic developmental interaction to which the child and parent is most accustomed, introducing a new dyadic partnership, that of child and professional, and to some extent incorporating new triadic interactions involving child, professional and parent.

The Portage worker is clearly not the first professional which the child and parent has had to deal with, and Portage input may in many cases be accompanied by continuing home-based input from therapists. However, it is probably the first educational professional with whom they have substantial practical interaction. Portage may therefore play a key role in not only consolidating a move from medical to social perspectives, but incorporating a socio-pedagogical orientation emphasizing learning through the child's social interactions, albeit here only with adults. Success in these interactions adds also the possibility that new aspirations can be created for the family in relation to their child, or that those which parents have already started to formulate themselves can be confirmed.

Timing may be important if the approach is to be influential in this way – input must be provided early enough, and then regularly enough to strengthen the expansion of the child's understanding and that of the child's parents. Important too may be the extent to which it is able to influence the perspectives and behaviour of all who are involved. As stated by Ákos and Ákos (1991), the child's interactions with a new, educationally oriented person may not only help the child to learn but also shape the

perceptions of the observing and participating parent. An extra likelihood is that the practitioner's perspective will also be influenced by the interactions which take place and by the parent's response to them. Indeed, the influence of both child and parent on professional practice is an important rationale for these triadic interactions. For this to happen, however, home-based work needs to be based on a solid understanding of socio-pedagogical values relating not just overall to children with disabilities, but to those with cerebral palsy in particular. The evidence from the literature in this study is, however, that the approach is generalized across different kinds of disability. There was little evidence in the empirical data too that the input was substantially influenced by the fact that the child had cerebral palsy rather than a different kind of impairment.

11.4.3 Therapies

Much of the evidence from parents, practitioners and local-authority personnel suggested a tendency to 'pigeon-hole' areas of children's development according to the professionals involved. Hence, improving children's posture, mobility and motor co-ordination was associated with physiotherapy, speech and communication with speech and language therapy, and children's play and cognitive development with less specialist educational and childcare services.

Physiotherapy in particular was seen as a central, prominent support service for all six target children represented in the study. This was largely predictable, as all experienced the kind of physical constraints and difficulties associated with cerebral palsy, albeit to differing extents. It also matched the widely documented professional viewpoint (Caro and Derevensky, 1991; Østensjø *et al*, 2003) that physiotherapy for such children is pivotal in helping them to gain and maintain physical health, retain physical skills they already have and perhaps gain new abilities in this area.

However, as evidenced by Fisher and Goodley (2007), Roffey and Parry (2014) and others, such therapeutic support is increasingly accused of being deficit-orientated, focusing on remediation of negatives more than on enhancement and utilization of a child's already held positive qualities. Either way, the interviews with parents and with practitioners suggested high levels of demand for these services. In the case of parents, there was little evidence that this demand arose from recognition of their child's previous physical progression resulting from this input. Much more it seemed to be because this service was most prominently recommended to parents at the time of their child's diagnosis of cerebral palsy. They had been told it was what was needed, they trusted that advice, and therefore felt they needed to campaign firstly to get it, then to get it with appropriate frequency and regularity.

Therapeutic input, in particular physiotherapy, was also the most explicit practical manifestation of multi-agency work, put forward in a myriad of Government pronouncements as the most effective way of meeting diversity in children's needs in the early years. However, in relation to the children with cerebral palsy, different educational practitioners had different interpretations of this obligation. Those with greater experience of work with children with cerebral palsy acknowledged the contribution made by non-educational professionals to children's overall support, but did not indicate any specific, regular effect on their own practice. Others with less previous involvement with disabled children in general and with those with cerebral palsy in particular were much more likely to draw explicitly on the expertise and advice of therapists. Indeed, for some this reliance became almost a blueprint for working with the child in educational activities. It affected – positively or negatively, depending on one's perspective – planning and design of curricular activities, the child's positioning and physical support, the use of prescribed assistive equipment and devices, and other aspects of children's educational routine.

11.4.4 Mainstream pre-school provision

In the outlooks of all research-participant groups, inclusive mainstream pre-school settings were principally associated with the child's social and cognitive development. They were also often seen as a source of children's social experience with peers, helpful in preparing the child for a move to full-time, compulsory education and indeed for later social inclusion within a wider society. Parents' wishes for their child to be embraced and appreciated in this provision corresponded with what Nutbrown and Clough (2006) saw as the ideal of inclusive practice.

However, some parents, including the two mothers with relevant teaching backgrounds, wanted such pre-school provisions to offer more than this. In line with Sutton's (2000) warning that children should receive not simply inclusive education, but good education, these parents questioned the adequacy of their child's experience in their early-years setting and the competence of the support they received there. They were not convinced about the overall benefit of the provision for their respective children. They were frustrated with the difficulties their children faced in keeping up with the pace and movement demands of mainstream routines and activities, as well as with what they saw as practitioners' disproportionate focus on cognitive learning in preference to a wider curriculum encompassing their child's development as a whole.

In terms of the practical contributions which families could make themselves to their child's care and education in these settings, little substantial evidence emerged in the study. Despite the policy outlook promoting parents as partners in service provision, examined in the literature review, reciprocal interactions between parents and practitioners in these contexts seemed limited to exchange of information and occasional discussion, and did not include more specific involvement in educational

practice. This may in part be due to the fact that the incorporation of a parent with their own child would not be customary practice generally in such pre-school settings – indeed it would be seen as detrimental to a child’s growing social independence – and that this outlook was applied to children with disabilities in that setting as well.

11.4.5 Specialized provision

According to official policy represented most clearly by the SEN Code of Practice (Department for Education and Skills, 2001), the majority of children with special educational needs and disabilities, including those with cerebral palsy, should attend mainstream education provisions. However, independent writers, such as Westwood (2013), have pointed out the benefits of more specialized educational settings.

This study’s parental survey indeed indicated that special, rather than mainstream nurseries were perceived as having good understanding of children’s needs, using social, environmental and educational adaptations to accommodate different levels of development and being flexible enough to encourage children to be independent. A further benefit of the specialist nursery was raised too: the possibility for continuity in education, giving confidence that a child’s complex needs might continue to be met as the years went by. The other principal specialist setting represented in the research, that of conductive education, was also regarded highly by the parents who knew it. They recognized its distinctively positive outlook on children’s disability and the opportunities it offered to pursue their child’s development in movement, mobility, self-care, interest and motivation in a way not convincingly offered in other provisions. Survey results indicated that children who received input at this setting were provided with challenging, but achievable goals and expectations to become active and independent.

The mother of the child attending conductive education was drawn in particular to the setting's understanding of her son's difficulties and needs, the positive attitude shown towards working with him, and the high expectations set for him which corresponded with her own. Her child, however, had a dual placement – three days a week at conductive education and two at a maintained special school. This approach reflected the view of Department for Education and Skills (2004) that voluntary bodies represent historically embedded services which complement statutory provision. However, the view of this child's mother, who wanted full-time conductive education for her child, more closely matched with perspectives expressed by Low (1998) and Miller (2000), which saw voluntary organizations as competitors for and challengers of their statutory equivalents. There was undoubtedly cause for tension at an empirical level in these differing perspectives.

In terms of parental contributions to their child's education in these more specialized settings, a more purposeful picture emerged than in the generalized mainstream settings. Contact overall was more regular, and at conductive education the first provision for the infant was parent-and-child work carried out together in a group. The nature of interactions in that provision was interesting here – outwardly triadic, in that professional, parent and child were involved, but essentially dyadic, carried out by parent and child together but directed and facilitated externally by a professional. The contrast with Portage work is clear – in Portage the professional primarily interacts with the child, while the parent watches; in conductive education the parent maintains her or his primary dyadic interaction with the child, watched and influenced by the facilitative professional. This may help to justify the claim of Jernquist (1986) that parents' involvement in a conductive-education group gives them confidence to relate developmentally to their child not just within sessions but in other contexts, most notably home, as well.

11.4.6 Overview

Overall within the range investigated, different settings had different profiles. They offered different services to their children with cerebral palsy, reflecting differing views on these children's needs. This variety was evident not simply in curriculum, but in the nature of professional qualification, experience and expertise on offer as well.

In the survey more than half of the 50 parent respondents drew on support from more than one service. Perhaps their rationale matched with those of parents who participated in a survey by Flewitt and Nind (2007), which suggested that parents use more than one early-years provision in the hope that all their child's needs will be adequately met.

11.5 What are these stakeholders' perceptions of the processes by which development and learning of these children takes place?

Progressing from understanding perceptions of the identity of the child with cerebral palsy and of the type of contexts they take part in, here 'process' is examined in order to shed light on the various ways in which stakeholders believe children's learning and development is – or should be – psychologically and pedagogically stimulated.

11.5.1 Psychological strategies

The literature review examined opposing views on whether it is the disabled infant or the parent who is more influential in establishing suitable 'attachment' in their

relationship. Also highlighted was the idea, in Ákos and Ákos (1991), Pianta *et al.* (1999) and others, that intensive dyadic interactions may actually lead to a stronger sense of attachment and subsequent benefits for both parties. Such strengthening can be particularly fruitful if it is used for the purpose of increasing the child's motivation, interest and independence, recalling Hári and Ákos's (1971, p122) ideas on 'dysfunctional' and 'orthofunctional' development in Chapter 3.

Increasing these qualities in children's play and other activities was a recurring theme in both surveys. Strategies to influence the child's motivation and confidence were in particular scored highly, both by parents and by practitioners, a possible indication of stakeholders' beliefs in the pertinence of children's emotional readiness for effort, trial and independent problem-solving. Interviewed parents generally did not identify these processes as a focus of support for their child – however, when these processes were felt to be absent in provision, tensions arose and differences in opinion on curriculum and approach between parents and practitioners emerged.

Practitioners' interviews shed more light on this issue, discussing a range of opportunities to increase children's confidence and motivation. These included play-based social interactions, extended encouragement and motivation in more demanding tasks, and use of concrete reward systems. The two practitioners working in specialist provision – conductive education and the special nursery – identified group-based activities, play as well as more directed tasks, to be as a powerful motivator. For the conductor this group work required high levels of organization, together with adult direction drawn from observation of the group as a whole and of individual children, although children doing a task as a group did not necessarily involve interaction between members of that group.

11.5.2 Pedagogical facilitation

Leach and Moon (1999) defined pedagogy as a 'mindset' adopted with regard to the learner and his or her learning, as well as to the outcome that is desired by the conscious action of educators. In relation to this concept, evidence suggested a range of ideas, in particular amongst practitioners.

In the survey, practitioners with less experience and confidence working with children with cerebral palsy, as well as those in interviews with either socially-oriented or individualized outlooks, tended to stress the adult's more than the child's role in learning. This view also incorporated, perhaps, a hint of justifying their own support role in the child's education. These practitioners also tended to emphasize another external factor in provision – environmental adaptations and the use of assisting devices – as important elements of successful learning for children with cerebral palsy. This viewpoint is also taken in much of the professional literature (such as Willis, 2009, and Westwood, 2013), and in legislation (Special Educational Needs and Disability Act, 2001; Disability Discrimination Act, 2005). For parents in the study, however, use of personalized equipment was not such a high priority. Perhaps they would agree with the conclusions of Huang *et al.*'s (2009) study which highlighted how such devices could be restricting for the child and impractical for use at home.

In contrast, the two practitioners with fairly substantial hand-on experience with children with cerebral palsy perceived the adult's role more as a facilitator than a director of activity or provider of equipment, and their thinking focused more on the child. Important to them in this respect was anticipation of children's own efforts and attempts, also the design of facilitative conditions, including provision of the minimal

support necessary for the child to have some independent success. Both saw that understanding of the child was imperative for this kind of approach.

The practitioner's view in conductive education in particular suggested resonance with Vygotsky's view on developmental consequences of disability and subsequent ideas to tackle these difficulties. For this interviewee, it was paramount to think about the child's all-round development in each activity, not focusing on the task and its completion by any means, but on the child's posture, his or her attention and interest, the independent effort shown and strategies used in attempting to succeed. In the survey parents too tended to see the ideal adult role more as facilitative than as controlling or didactic, a process of recognizing and activating the child's interests, rather than giving full support and 'overtaking' the task. Ákos and Ákos (1991) identified this approach as the adult being there to do things in a way that the child enjoys, rather than taking control away or remaining distant.

The local-authority personnel interviewed in the research recognized that there were differences in practice amongst different kinds of provision, although they did not describe such differences in quite this way. Their major concern in relation to process was the lack of experience and training amongst some staff, together with a high staff turnover, in particular in privately or voluntarily run mainstream settings. The support services they managed tried to address these issues by providing both practical advice and professional-development opportunities. However, the outlook these represented was rather generalized, relating in a wide sense to development and learning of all children with disabilities, and lacking, from some perspectives, more pedagogically specialized and personalized elements applicable to children with cerebral palsy.

11.6 In relation to time, how are future priorities and possibilities for the development and learning of these children viewed by these stakeholders?

This fourth research question addressed the final aspect of Bronfenbrenner's model: 'time'. In contrast with the first three questions, discussion here does not focus on research participants' reflections on the past and perspectives on the present. Instead it considers how they perceived their children's future development and the type of education and support their children needed to achieve best progress.

According to Wolman *et al*, (2001) parents of disabled children are generally more positive about the present than about the future. The parental survey and interviews did not suggest this difference, however. In the data, parents' expressions of appreciation and concern about the present were matched by the combination of aspiration and anxiety about their child's future.

Their more affirmative perspectives, in which both the child's strengths and difficulties were recognized, reflected a degree of confidence about how things would turn out. The fact that the negative predictions about their child which some had heard earlier had not been realized may have helped in this. For instance, children perceived as having been 'written off' by medical professionals at the start of life because of the apparent severity and complexity of their condition had exceeded expectations in their development. Their parents were perhaps justified, therefore, in having matching high expectations for the future too. Overall, positive aspirations seemed part of a determination amongst parents to do their best for the child and to see their child do their best for themselves.

These elements of optimism did not suggest injudiciousness. Parents of the children with more complex difficulties still saw the future as something of an unknown entity,

even though they could envisage their children continuing to make small-step progress and be happy and self assured in themselves. A degree of uncertainty in their case was not a particularly negative phenomenon, but more a feature of previous experience, one likely to continue into the future.

Parents, in the first instance, drew on children's strengths in character, social competence and interests to justify these positive positions. Evidence from the practitioners' survey complemented these parental outlooks: social elements were scored highly, with children's participation in play and communication with other children and with adults regarded as priorities for future provision. However, positive expectations were accompanied too by what Wolman *et al.* (2001) saw as a fearfulness felt by parents about their child's acceptance in peer contexts and within society in general. When transition from one setting to another was discussed in the current study, this anxiety was particularly often expressed.

11.7 How is this range of outlooks evident in observed practical interactions between children and practitioners?

To address this final question, understanding derived from the previous research questions was integrated with evidence obtained from observations of interactions between the six target children and their professionals in their educational settings. Discussion here focuses in particular on similarities and contrasts between stakeholder perspectives on the one hand and children's observed experiences on the other.

As seen in the literature review, authors such as Oliver (1990), Goodley (2001) and Shakespeare (2006) have pointed out how outlooks on disability permeate into

systems, procedures and professional practices. This idea was confirmed by the integrated evidence in this study. In parents' perspectives, identities of their child altered and overlapped, framing expectations for their child's development as well as for the professional support they should receive. In contrast, practitioners' perspectives more consistently suggested one or other orientation – social, medical or pedagogical – and this was evident too in their professional practices. For instance, the interactions of the practitioners who in interview allied themselves more with a socially underpinned outlook showed a preference in their practice to focus on children's social well-being and proficiencies and to use the child's social niches to accomplish competence. Others, who perceived the children's development and learning from a more medicalized point of view, with emphasis, for example, on mobility or hand co-ordination, were subsequently seen to target these specific elements in practice and in the support strategies they applied to the child. Overall, therefore, what practitioners conveyed in their interviews, they reinforced in their own professional practice.

Greater variation emerged from the two practitioners with a more pedagogically oriented perspective. Perhaps because of a conscious or unconscious understanding of the Vygotskian outlook on the socially constructed nature of children's development and learning, as well as a belief in the power of the peer group in motivating children's interest and level of activity (Hári and Ákos, 1988), they claimed in interview to use peer-group activities as strategies to enhance children's participation, activity and thereby their learning. However, while observations in their settings confirmed the use of a children's group in their practice, interpersonal relationships within that group, between peers, differed between the two settings.

In the special nursery the child's complex difficulties meant that practitioners' intention to help her to be more independent was difficult to address without a

continuous dyadic scenario. In conductive education such one-to-one support was also frequently evident, but the child's interpersonal relations with others were continuously increased or decreased by practitioners moving about. Dyadic interactions therefore played a key role in children's learning here too, but these were more temporary and intermittent in conductive education than in the special nursery, being altered, reduced or withdrawn when the child's level of interest and independence were raised, or intensified when the child faced particular challenges solving a task.

Such modifications were accomplished by conductors observing and gauging each child's activity and learning in relation to other children. When a child was judged to be in need for additional support, the whole group's activity was also often adjusted, for instance by repeating or sustaining activities, raising awareness of children's performance and celebrating each other's successes. Such processes indicated complex orchestration of group work which accommodated each individual child's needs.

This process was helped by the fact that group work in the conductive education setting was sustained within a shared framework of tasks which were differentiated, simplified or advanced according to each child's individual level of development. This meant that the child did not face substantially difficult tasks, but, through differentiation, only tasks a little beyond what he or she was capable of performing. Verbal or manual facilitation or use of equipment gave the extra help where it was necessary for the challenge of a task to be overcome, still largely through the child's own efforts. The process evidenced therefore a more sophisticated manifestation of recognition of a 'zone of proximal development' than simply providing help so a task completed by all children could be completed for the child with the disability also.

Alongside observed differences in practice, there were other aspects which were shared across all settings. All practitioners showed consistent respect and concern for the children's generic well-being, appreciated their personalities, understood their interests and recognized the child's effort and achievements. This occurred even when evidence from interviews indicated that practitioners did not share similar outlooks with parents or agree with parents' priorities for their child. A reason for this was likely to be their own professional interest and regard for children in general and for working with disabled children in particular.

Parents participating in the study had specific expectations towards professionals working with their children, confirming Read's (2000) suggestion that they appreciate good professional services. In the current study, they wanted them to understand their child's overall individual needs and to provide appropriate support so she or he could participate, show effort and learn. As has been seen, quality in professional work in the early years has been a recurring theme: in government policy, from Department for Education and Skills (2004) to Department for Education (2011); in research (Rumbold, 1990; Russell, 2003; Flewitt and Nind, 2007); and in the broader professional discourse (Horvath, 2006). Nevertheless, as was recognized by the heads of two local-authority based support services, some practitioners lacked confidence, experience and expertise to meet demands relating to these children, and data from the practitioner survey gave further evidence of this.

Observations of practice showed differences between the approaches of practitioners with substantial and of those with little experience and expertise. For most across the six settings, support for the children involved a spectrum of social and emotional stimulation, encouragement and explanation. When this did not work, practitioners with less experience used various approaches. One was to take over control from the child so that the task could be completed. Another was to divide

different aspects of helping the child between different adults, with the physical aspects of support left to the teaching assistant, who invariably herself took over control when the child was unsuccessful in her trial to accomplish a task. A third approach involved educators supplementing their teaching role with an acquired role of therapist, employing strategies of repetitive and passive exercising and activities with the child derived from this latter role, and in doing so lessening social interactions with other children in the setting and denying the child opportunity to choose his or her own play activity.

In contrast to these, the two more experienced specialist practitioners used a wider combination of psychological and pedagogical strategies. They altered and adjusted the level or nature of their facilitation, and used a range of organizational, psychological and linguistic means to encourage, maintain and enhance the children's interest, level of motivation, participation and activity. These scenarios illustrated Hári and Ákos' (1988) and Hári's (1997a) assumption that cerebral palsy becomes detrimental for a child's development and learning if the child cannot accomplish his desires and wishes.

Qualitative differences were evident in the physical environments of settings too, more specifically in how these environments encouraged or restricted the possibilities for movement and socialization for the child with cerebral palsy. Three of the six observed settings were spacious mainstream, 'inclusive' pre-school environments, having a large amount of attractive, child-centred toys and other resources. These environments reflected concerns to provide a broad range of child-initiated and adult-led activities, indoor and outdoor, as well as the 'enabling environment' for young children demanded by the EYFS curricular framework.

For the observed children, however, such arrangements seemed to restrict more than to enable. Their need to move across long and crowded distances reduced their independence and increased their dependence on adults. Their use of unadapted 'ordinary' toys and other resources created similar difficulties. In these circumstances, the over-use of personal equipment such as wheelchairs, often to facilitate the giving of adult help during educational routines, also invariably distanced the child from the peer group, reducing opportunity for social experience and close interaction with other children.

Finally, observations highlighted a characteristic of the children themselves, of their 'person'. This can be called their 'charisma', and is a reminder of what several parents said in interview about their child developing a will of their own. During both their enjoyable and their more difficult activities, the observed children appeared strong in their wishes and desires, in what they wanted to do, how they wanted to do it and when they preferred not to do it. Despite the difficulties with mobility, with use of hands and with communication, and even perhaps because of these restrictions, when motivated and wishing to do something the children invariably showed a high level of determination to accomplish it. When such 'signals' were misinterpreted, missed or ignored by practitioners, they showed disappointment and lost interest, but when allowed or encouraged to do so, they showed perseverance in reaching their goals.

11.8 Implications for practice

Addressing each research question through integrated evidence from all data sources brings the study back to its original objective, described in Chapter 1. This objective was to develop a more explicit outlook on the early development and

learning of young children with cerebral palsy, conducive to informing social and educational dialogue and understanding of ways in which their learning and development can be supported. The objective was pursued through seeking fresh perspectives, with a view to stimulating change in understanding of their support needs and influencing the processes by which their early development and learning is considered and addressed in early-years educational practice.

11.8.1 Pedagogy and upbringing

As discussed in Chapter 1, contemporary Western discourse so far has not yet reached consensus regarding what constitutes pedagogy (Alexander, 2004; Papatheodorou, 2007). It is broadly agreed, however, that the notion refers to an attitudinal stance taken towards the learner and his or her learning, underpinned by particular values which are reflected in desired outcomes of the social or educational activity (Leach and Moon, 1999; Daniels, 2001). The discourse of social pedagogy, traditionally rooted in central and eastern European, and in particular in Soviet educational traditions, offers a more explicit platform for closer interrogation of this concept. In this study, views from Vygotsky, Sukhomlinsky, Sutton, Hári and Hári and Ákos have been particularly enlightening in this respect.

Vygotsky (1991) defined pedagogy as the science of the upbringing of children. It is discourse actualized in the whole social process of bringing up a child. Strategies derived from this pedagogy therefore extend not simply to standard curriculum objectives or specific individual targets, but beyond that, as explained by Bakonyi and Szabadi (1971), Kraevskii, (2002), Sukhomlinsky in Cockerill (2009), Millei (2011) and Smith (2013), to concern for the nurturing of a child's socialization through all-round development, including strengthening of their identity, character

and independence, together with strengthening of the contexts in which this development takes place.

11.8.2 Identity and pedagogy

In relation to identity, the most persuasive picture of the developing and learning child with cerebral palsy is created where social, medical and educational identities closely intertwine. For parents, this complex image emerges over time, with an interactive balance attained as the result of alterations in the child's relations and activities. A similar equilibrium, if sometimes less intricately integrated than that of parents, is also achievable by practitioners when they gain all-encompassing understanding of the child's needs and the confidence and expertise to support children's all-round development.

This identity, more complex and pedagogically oriented than traditional medicalized and social orientations, is seldom fully appreciated in professional discourse, or indeed in practice relating to these children. In order for early intervention – and more specifically for inclusive early education – to fulfill its role in providing children with cerebral palsy with well-established foundations for future learning (Department for Education, 2012), there is a need to supersede medical and social identities of the child with a stronger learning identity, one which recognizes and understands not simply the primary implications of the cerebral-palsy condition, but also its secondary social and psychological consequences (Hári and Ákos, 1988; Vygotsky, 1993; Sutton, 2008).

If current trends of early-years education in England, as well as wider liberal, democratic and humanistic ambitions of English society in general are taken into account, this more encompassing identity should be formed not in isolation or in

segregated environments, but as part of an inclusive social and educational agenda. For it to emerge there is a need for shared and unambiguous language about and understanding of the implications of cerebral palsy, together with an all-entailing and integrated outlook, rather than one divided into separate developmental aspects. The basis for such thinking may be already evident in aspects of some social and professional discourses and practices, in particular as part of the natural processes of parenting at home. However, incorporation of such understanding needs to take place in terms of more overtly pedagogical thinking if it is truly to inform the developmental and learning prospects of these children.

11.8.3 Context and pedagogy

Enhanced pedagogical thinking in relation to these children should also be accompanied by enhancement of contextual conditions that create and strengthen opportunities for the kind of social interactions which, in the Vygotskian perspective, act as the prime medium for children's development and learning. An important area in this respect is professional training for practitioners, as highlighted previously by Buell *et al.* (1999) and Flewitt and Nind (2007). Such training should not simply be concerned with describing cerebral palsy in conventional ways and stereotypically providing 'know-how' instructions for practitioners about what to do. The principal focus needs to be on pedagogical values which demonstrate understanding of the implications of cerebral palsy on the child's socialization and development of higher-level psychological functions. As part of this, parents could work more closely and meaningfully with these provisions and share their more all-encompassing perspectives and experiences to accomplish a shared sense of thinking and practice.

If appreciation of pedagogy is imperative for improving social and educational contexts for these children, there is also the opportunity and a need to address the

dilemmas of difference identified by Norwich (2008). In particular, considering how to balance the need for distinctive provision with generalized values and principles of child development will help the discourse of special educational needs in general and that relating to children with cerebral palsy in particular to advance further from the Education Act's (1971) seminal, basic insistence that all children should have a purposeful education.

11.8.4 Pedagogy and practice

Bearing in mind the practical difficulties observed in this research in relation to children's access to the physical environment, to useable resources and to opportunities for socialization, development for children with cerebral palsy needs to be seen very much as an interactive process (Sutton, 1988; Moore, 2000; Daniels, 2001; Smidt, 2011). At an empirical level, there needs to be close professional scrutiny of how children's participation with peers in play and other social activities is facilitated.

This might also encourage more enlightened thinking about how a wider spectrum of strategies for enhancing children's independent learning and development might be employed. This would involve practitioners and others developing priorities and approaches which are not simply fixated on one or another element of the child's learning or perceived difficulty, then leaving others for non-educational professionals to deal with, but recognizing the complex, holistic range of functions and attributes which lead to performance by a child, in particular the psychological qualities of motivation, interest and desire, which stimulate development and growth.

Finally, the spectrum of outlooks interrogated in this study highlight how a more positive perspective is created with regard to the children's futures. When the child is

regarded as a capable learner, with clear expectations and goals for his or her holistic developmental progression (Hári, 1997a), and when pedagogical strategies are conducive to accomplishing such child-related aspirations, then not only is a more optimistic picture of the child created, but a more positive purpose for the wide and important processes of upbringing is secured.

11.9 Review of research design

The rationale for employing Bronfenbrenner's (1995) bio-ecological model as the framework for this study was explained in Chapter 2. The model's systematic and all-embracing outlook steered the research design, providing structure for the research questions, offering a logical framework for critical review of relevant literature, directing attention to potential data sources, helping to clarify data analysis and informing the configuration of findings.

Overall, the model's elements aided conceptualization of development and learning of children with cerebral palsy as a range of interactive influences, rather than a configuration of one or more discrete deterministic factors. Person-related characteristics, contextual issues, interactive processes and the element of time were all manifested as important, intertwined ingredients of stakeholders' portrayal of development of these children, and these perspective were additionally sought and examined when children themselves were observed in everyday practice.

11.9.1 Scope and complexity

The most prominent challenge posed by use of the PPCT model related to its scope and complexity, and therefore to the scope and complexity of this investigation.

Bronfenbrenner designed his framework as an all-encompassing picture of how a young child's development was formed and how its interacting influences could be examined. He spent a lifetime adding to it and refining its key elements. This study was informed by his later, most complete model, where its scope and complexity are most extensive.

Bronfenbrenner was certainly not short of ideas – however, his system has never been tested in its entirety (Thomas, 1996). Indeed, to employ all of his propositions even within a larger-scale study would be unrealistic. Instead, its complexity and scope have to be managed in some way, particularly when the study is relatively small-scale.

In this research, therefore, decisions had to be made about how much to include and how much to examine without compromising the model's underpinning principles. In order to reducing scope, one approach could have been to choose to investigate only one or more parts – 'context', for instance, or 'process', allowing a more explicit focus on selected elements. However, this would have invalidated one of the framework's essential features, its interconnections across all elements. Bronfenbrenner did not simply identify four separate areas for attention, he provided a whole, interlinked web of reciprocating factors – personal, contextual, procedural and progressive – all in his view interactively playing a part in the forming of the young child. Choosing just some of these would have meant the researcher losing not just scope, but its complexity too, compromising the idea, illuminated, for instance, in Sontag (1996), Smart (2008) and Llewellyn *et al.* (2010) and pursued in this study, that the experience and influence of disability is a complex and interactive rather than a straightforwardly deterministic phenomenon, and therefore leading to what Tudge *et al.* (2009) identified as a common problem with application of the bio-ecological model: misconception and misinterpretation.

This problem was potentially made worse by adopting a case-study design for the investigation as a whole. As was seen earlier in this study, case study requires that investigation be carried out in depth, a particularly difficult task when a model with substantial scope is adopted. Paradoxically, however, it is here that a solution for this researcher lay. The Bronfenbrenner model has this depth itself, precisely because it seeks complexity of thinking in its interconnected conceptualization of a child's development. The PPCT model provides not just breadth of vision – its scope, but depth of scrutiny too – its intricacy. By using it in this case-study investigation, this researcher had opportunity to achieve both in her enquiry.

The final strategy adopted, therefore, was pragmatic, but not often examined or adopted by research informed by Bronfenbrenner's framework. It was to limit and define the focus of the elements of the model in the investigation. The researcher chose a particular component to examine to represent each of these, taking a bounded stance to each interconnected strand. While a complete picture of everything was not, and indeed could never be attained, this approach protected both breadth and depth of scrutiny and safeguarded the model's interactive complexity.

Examination of the first element of Bronfenbrenner's framework therefore focused on how the child was perceived as a developing 'person' with the disability of cerebral palsy. Analysis of 'context' recognized the multiplicity of contexts playing a role in children's nurturing, but limited its focus to particular social and educational niches. In relation to 'process', the research principally interrogated interfaces between child and educator, while 'time' was interpreted not as a whole longitudinal element of the investigation, but as a specific aspect of the thinking of stakeholders relating to each child's developmental and educational future.

This approach enabled the researcher to make use of the model in its entirety, retaining its connectivity between all four elements. Furthermore, it allowed the investigation to fulfill the promises offered by Stake (2005), Yin (2009) and so many others that a case-study strategy would provide opportunities for in-depth scrutiny of the chosen issue.

11.10 Limitations of the thesis

Even with this approach, the research topic remained challenging to undertake within a single, small-scale investigation. Bronfenbrenner's four elements and his expanding range of system-levels created a need to examine and integrate many different, but relevant issues. Account also had to be taken of the intricate and often ambiguous nature of the current agenda and discourse of special educational needs, influenced by the literature of various fields: disability, family, early-years studies, social welfare and rehabilitation. Researching the issue was therefore a difficult task, and maintaining concentration on the study's pedagogical aspirations was a particular challenge. Instrumental in dealing with these aspects were ideas from the international pedagogical discourse on cerebral palsy, and in particular Vygotsky's (1993) specific outlook on the development and upbringing of disabled children.

A specific limitation of the study related to data obtained from the parental survey. As explained in Chapter 4, more than half of questionnaire respondents were associated with conductive education. This provision was not part of the authority's early intervention mechanisms, but a voluntary-sector service accessed by families. On a positive note, the inclusion of the views of respondents with experience of this specialist service allowed more broadly based perspectives to be collected. On the

other hand, findings may have been unduly influenced by the fact that no other provision was represented to this extent in this aspect of data collection.

A more empirical area of difficulty was the involvement as research participants of children themselves. While parents and practitioners may be able to represent children's viewpoints meaningfully at least in part, these sources cannot be seen as substitutes for the children's own voices. It was important, therefore, to give children's perspectives a place of some kind within the investigation. For practical and ethical reasons, the study ultimately involved children only indirectly, by means of observing their behaviour and responses within interactive situations with adults. If the study were to be deepened with further research, closer participation of children themselves might offer a means of evaluating current findings and extending these further in meaningful ways. This could involve balancing setting-based observations with those conducted in other social settings, such as the family, as well as developing a data-collection tool which was receptive to the age and ability of children in order to capture verbally or non-verbally their views and experiences.

Likewise, the thesis was conducted in a professional field that is multi-disciplinary in nature. It includes strong influences from health-related and therapeutic discourses and practices, evident to some extent in practitioner interviews in the study. However, again for reasons of scope, and because of the significant ethical barriers to exploring health-service related issues in research, therapists were not included in the investigation. Within a different or more extended study, this is another area of investigation which might be addressed.

11.11 Role of the researcher

As explained earlier in Chapter 1, then reiterated in section 4.8, the researcher's interest and engagement with this study grew from her own extended professional experience of work with young children with cerebral palsy. Unarguably in the research, therefore, her own values concerning the development and learning of these children influenced the ways by which research participants' outlooks and practices were captured and then interrogated. Such a position has inescapable implications for the objectivity of outcomes, reinforcing a requirement for increased academic scrutiny of the processes by which they were attained. It is important at this stage, therefore, to reiterate the steps undertaken to strengthen trustworthiness and integrity of the investigation.

Chapter 4 clarified the range of strategies undertaken to increase validity and reliability of the study. These steps were underpinned by a reflexive approach, which involved ongoing and increased scrutiny of the role of the researcher recommended by Aubrey (2000). Contributing to such reflection were close collaboration with the thesis supervisor, extended involvement with the settings, data checks with research participants, and presentation and discussion of aspects of the study at various academic events.

Nevertheless, it was also essential to recognize Richards' (2009) assertion that a tool that would fully purify subjectivity from a research process does not exist. Instead, the personal experiences which the researcher brought to the study were used for the benefit of the investigation. In particular it was possible to extend its range and distinctiveness by drawing on elements of understanding concerning education and parenting of children with cerebral palsy which are less evident or emphasized in the

Western discourse. In this respect the researcher's background and personal outlooks proved instrumental, rather than detrimental in producing conclusions.

11.12 Recommendations for future research

This investigation examined the different ways in which early development and learning of young children with cerebral palsy is perceived by social and educational stakeholders and the ways in which these perspectives are evident in children's early educational experiences. The study drew substantially from writings of Ákos and Ákos, Hári, Hári and Ákos, Sutton and others with special interest in pedagogy and upbringing of children with cerebral palsy.

These writings, however, were published for the most part around twenty years ago. More contemporary literature, in which pedagogical identity of the child with cerebral palsy is promoted in an integrated fashion alongside the separate medical and social orientations already upheld, has yet to be produced. Achieving this may involve confrontation with the current, more imprecise and outdated discourse of special educational needs, as well as with the compartmentalized consideration of children's development and learning which has accompanied it. Future research may focus on this deficiency.

A second recommendation relates to conductive education, which in this study was captured as having the most detailed and explicit pedagogical understanding and confidence in meeting the needs of children with cerebral palsy. Parent participants with experience with the provision also communicated the benefits derived from such characteristics. As explained in the literature review, conductive education has been a controversial approach in the English context, consequently becoming more often a voluntary or privately secured educational option than part of statutory provision. In

the view of Sutton (2014) research has remained a big tension in strengthening its standing. Yet exploring and explaining the social and pedagogical values would advance understanding of the nature and distinctiveness of its practice (Lambert, 2004). Certainly, according to findings of this study, its knowledge base and practical expertise could be a potentially highly valued aspect in attempts to develop a stronger national discourse regarding contemporary support for young children with cerebral palsy and their families.

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APPENDIX A: INFORMATION ABOUT THE RESEARCH

‘Supporting the early development and learning of young children with cerebral palsy’

Doctoral research study 2008-13
Tunde Rozsahegyi, University of Warwick

MYSELF

I am Tunde Rozsahegyi, I work as Senior Lecturer in Special Needs and Inclusion studies at the University of Wolverhampton, based at the Walsall Campus. My background is a teacher in special education, in the UK and abroad.

I am currently registered for a PhD study at Warwick University; my supervisor is Professor Carol Aubrey.

MY RESEARCH

My doctoral research is examining the perspectives of parents, educational practitioners and policy makers about the early development and learning of young pre-school children with cerebral palsy. I am carrying out this investigation in Local Authority in the West Midlands in order to develop ideas about educational priorities for these children within the early years.

I am not seeking to judge the quality of provision, either in the local authority or in particular settings or to make comparison between settings or practitioners. My objective is to use the various perspectives to examine my topic in detail, finding commonalities and differences in pedagogical thinking regarding these children.

METHODOLOGY

My investigation is an exploratory study - I am looking at the experiences and ideas of those who contribute to children's early years education and upbringing before these children start formal schooling. Data for this is being sought from interviews, observations and a survey questionnaire to be distributed amongst those involved in the upbringing and education of these children.

The survey is designed to involve a broad range of practitioners in the research. The questionnaire will be distributed in each setting to all involved with the early years education, support and day-care of these children; it will also be given to parents. Your help in facilitating distribution is much appreciated. Completion of the survey is voluntary.

Interviews will take place in one-to-one settings. I will inform participants about the areas of my interest beforehand. Time and venue will be arranged for the convenience of the interviewee. Interviews will be voice-recorded if the interviewee agrees – if not, then I will take written notes.

I will carry out a series of observations in different early years and other settings, allowing me to look at different aspects of the child's educational provision. These observations will be arranged at the convenience of the setting itself, once parental

consent is received. Some observations will take place at the children's home setting if consent is given.

CONSENT

All aspects of my data collection will be carried out with the informed consent of those taking part and according to each setting's policy regarding permission from parents or from staff.

CONFIDENTIALITY

All data, including the name of the setting, managers and head teachers, practitioners, parents and children themselves, will be anonymised. I will keep transcripts of the interviews on my home computer which is password-protected and backed up on the system of my place of work, also password-protected. A copy of the transcript and the relevant recording will be available to all interview participants.

I will use the transcribed data only for the purpose of the study and area related to my research. When I am satisfied that no further use can be made of the interview tapes or the written transcripts, I will delete them.

SAFETY

I have approval to carry out this study from the Research Ethics Committee of Warwick University. I have enhanced disclosure from the Criminal Records Bureau which is available for your scrutiny.

FEEDBACK

Following interviews and observations I will share with research participants the transcript of the data recorded during discussion or as a result of observing practice and will invite you or your colleagues to check these and make comments before analysis takes place.

I will be pleased to share the results of my study with those who have kindly agreed to take part in the research.

FURTHER INFORMATION

If you would like more detailed information about this research, or would like to discuss your participation, please get in touch. Initially by email is usually best.

My contact details:

Tunde Rozsahegyi
School of Education, University of Wolverhampton
Gorway Road
Walsall
WS1 3BD
Telephone: 01902 323372
Email: tunde@wlv.ac.uk

APPENDIX B: PARENTAL QUESTIONNAIRE

October 2011

Dear Parents,

QUESTIONNAIRE: Supporting development and learning of young children with cerebral palsy

I am Tunde Rozsahegyi, I work as Senior Lecturer in Special Needs and Inclusion Studies at the University of Wolverhampton, based at the Walsall Campus. My background is in special education both in the UK and abroad. I am currently registered for PhD study at Warwick University.

My research is examining the views on early education and upbringing of young, preschool children who have been having cerebral palsy. For this I will analyse a range of views, such as the perspectives of parents, personnel from local authority-based support services and practitioners working with the children. I will also observe children's own experiences in practice. The research will be carried out in a range of early years educational and day-care settings in the West Midlands. Obtaining parents' views and experiences regarding their child's support in these settings is imperative to complete this research.

I have given you this questionnaire because I understand that your child attends and receives support to enhance his/her development. The questionnaire will also be given to other parents whose children need support to enhance their early physical skills.

I would be very grateful if you could complete this questionnaire and return it in the envelope provided. It should take you 5-10 minutes to complete. This questionnaire will be fully anonymous and confidential; I will not identify you in any way in any conversations, presentation or report about my research.

If you would willing to participate in other aspects of the research study (i.e. discussion), please provide your contact details at the end of the questionnaire.

If you would like more detailed information about this questionnaire or the study itself, or wish to discuss your participation, please contact me.

Your time and contribution is greatly appreciated.

Best regards,

Tunde Rozsahegyi
School of Education, University of Wolverhampton
Gorway Road
Walsall
WS1 3BD
Telephone: 01902 322866
Email: tunde@wlv.ac.uk

**Supporting development and learning of young children with cerebral palsy
Questionnaire for parents and carers**

Please answer each question according to the instructions. Thank you for your time.

1) Please indicate your gender:

Female ☐ Male ☐

2) What do you consider to be your ethnic origin? Please tick one box:

White British		Asian Pakistani	
White Irish		Asian Indian	
White (other)		Asian (other)	
Black British		Chinese	
Black Caribbean		Mixed White and African	
Black African		Mixed White and Asian	
Mixed White and Caribbean		Other ethnic background, please specify:	

3) Your relationship to your child? Please tick one box:

Mother	
Father	
Legal carer	
Grandmother	
Grandfather	
Other (please specify):	

4) How old is your child who has cerebral palsy? Please tick one box:

0-1	1-2	2-3	3-4	4-5	5+

5) Gender of this child, please tick: Male ☐ Female ☐

6) Do you have any other children? Please tick one box:

No ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐

7) What sort of early educational provision does your child participate in on a regular basis? Please tick as many boxes as apply:

1.	Private day-care nursery	
2.	Nursery unit attached to primary school	
3.	Reception class in mainstream school	
4.	Nursery unit at a special school	
5.	Reception class in special school	
6.	Day-care nursery in children centre	
7.	Specialist nursery	
8.	Short breaks	
9.	Child minder	
10.	Portage work	
11.	Local play-group	
	Other provision, please specify:	

8) In your opinion which one of the above is the most useful for your child?

☐

Please explain why:

9) Listed below are some aspects of development. Please choose three of these which in your opinion receive the most attention from practitioners who work with your child. Please rank them so that 1 = the aspect which receives the most attention 2 = the next most attention, and 3 = the next most attention.

1.	Physical skills (e.g. sitting, standing)	
2.	Hand skills	
3.	Communication	
4.	Behaviour	
5.	Mobility	
6.	Cognitive skills	
7.	Social skills	
8.	Self-care skills	
9.	Other, please specify:	

**10) Are there any areas above where you would welcome more attention or input?
Please indicate the numbers in the boxes below, so that the area which is most important to you is in box 1, the next most important is in box 2, and the third most important is in box 3.**

11) Please indicate according to your experience how developing the skills listed below is affected by your child's cerebral palsy? Tick one box for each skill:

	Affected a great deal	Affected to some extent	Affected a little	Not affected at all	Not Sure
Moving around					
Using hands					
Playing with objects					
Playing with others					
Communication					
Speech					
Making themselves understood					
Understanding					
Paying attention					
Socialising					
Confidence					
Motivation to do things					
Eating and drinking					
Toileting					
Dressing					
Sleeping					
Generic health					
Any other? Please specify:					

**12) In your opinion what are the priorities for development and learning for your child?
Please tick one box for each area:**

	Very important	Important	Not very important	Not important at all	Not sure
Playing individually					
Playing with other children					
Using hands at table-based activities					
Moving about					
Communicating with other children					
Communicating with adults					
Eating and drinking independently					
Dressing					
Toileting					
Carrying out special tasks prescribed by therapists					
Using specific equipment provided by therapists					
Encouraging general participation in activities					
Influencing behaviour					
Dealing with medical demands					

13) In your experience how important are the following strategies in supporting the development and learning of your child? Please tick one box for each strategy:

		Very important	Important	Not very important	Not important at all	Not sure
1.	Changing the environment for easy access					
2.	Adaptation of toys, tools, equipment					
3.	Providing more time					
4.	Simplifying activities					
5.	Providing specific activities					
6.	Letting the child to learn by trial and error					
7.	Letting the child choose whether or not to participate					
8.	Providing continuous one-to-one support					
9.	Increasing motivation					
10.	Building confidence					
11.	Providing repetitive opportunities for practice					
12.	Giving continuous positive reinforcement					
13.	Telling the child what to do and how					
14.	Providing technology to enhance independence					
	Having consistently high expectations					
	Any other? Please specify:					

14) In your opinion which three of the above strategies are the most important for your child's development and learning?

☐☐☐

15) Do you have any other comments to make in respect of priorities for development and learning of your child?

THANK YOU FOR YOUR TIME. YOUR CONTRIBUTION TO THE RESEARCH IS GREATLY APPRECIATED.

I would be grateful if you could provide some details, so I can contact you to discuss some further aspects of the research. These would include observing your child in the nursery and a short interview with yourself to discuss your experiences in more detail. Thank you.

Name: _____

Phone: _____

or

Email: _____

PLEASE RETURN THIS QUESTIONNAIRE IN THE ENVELOPE PROVIDED.

APPENDIX C: PRACTITIONERS' QUESTIONNAIRE

February 2012

Dear Respondent,

QUESTIONNAIRE: Outlooks on the early development and learning of young children with cerebral palsy

I am Tunde Rozsahegyi, I work as Senior Lecturer in Special Needs and Inclusion Studies at the University of Wolverhampton, based at the Walsall Campus. My background is a teacher in special education, in the UK and abroad. I am currently registered for PhD study at Warwick University.

My research is examining the outlooks on the early development and learning of young, preschool children with cerebral palsy. For this I will analyse a range of views, such perspectives of stakeholders (parents, practitioners, managers of local authority support services). I will also observe children's own experiences in practice. I will carry out my research in a range of early years educational and day-care settings in Local Authority.

I have given you this questionnaire because according to my understanding you are working with or responsible for supporting the development and learning of young children with cerebral palsy. This questionnaire is given to a range of practitioners and centre managers as well as parents of these children.

I would be very grateful if you could complete this questionnaire and return it in the envelope provided. If you wish to participate in other aspects of the research study, please provide your contact details at the end of the questionnaire.

Everything you write will be treated anonymously - I will not identify you or your setting in any conversation, presentation or report about my research. When I no longer need to keep the completed questionnaires, I will destroy them.

If you would like more detailed information about this questionnaire or the study itself, or wish to discuss your participation, please contact me.

Your time and contribution is greatly appreciated.

Best regards,

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**Supporting the early development and learning of young, pre-school children
with cerebral palsy
Questionnaire for early-years practitioners**

Please answer each question according to the instructions. Thank you for your time.

1) Please indicate your gender:

Female ☐

Male ☐

2) What do you consider to be your ethnic origin? Please tick one box:

White British		Asian Pakistani	
White Irish		Asian Indian	
White (other)		Asian (other)	
Black British		Chinese	
Black Caribbean		Mixed White and African	
Black African		Mixed White and Asian	
Mixed White and Caribbean		Other ethnic background, please specify:	

3) What is your current role? Please tick one box:

Child minder		
Early years practitioner		
Early years teacher		
Conductor		
Higher level teaching assistant		
Learning support assistant		
Head teacher		
Centre manager		
Local authority representative		Please specify:
Therapist		Please specify:
Other		Please specify:

4) What type of setting do you work in? Please tick as many as apply:

LA-maintained day-care nursery	
Nursery unit attached to primary school	
Foundation unit as part of primary school	
Nursery unit attached to special school	
Foundation unit as part of special school	
Independent day-care nursery	
Nursery unit in children centre	
Child-minding	
I work with children in their homes	
Voluntary organisation. Please specify:	
Private organisation. Please specify:	
Other. Please specify:	

5) What is your highest qualification? Please tick only one box:

NVQ Level 2 (or equivalent) ☐ please specify: _____

NVQ Level 3 (or equivalent) ☐ please specify: _____

NVQ Level 4 (or equivalent) ☐ please specify: _____

GSCE ☐

A-level ☐

Generic degree ☐ please specify: _____

Honours degree ☐ please specify: _____

Post-graduate qualification ☐ please specify: _____

Other qualification ☐ please specify: _____

6) How many years' practical working experience in early years (0-5 years) do you have in total? Please tick one box:

None, I am not a practitioner	0-2 years	3-5 years	6-10 years	11-15 years	16-20 years	20+ years

7) How many years' experience do you have in total working with children with SEN?
Please tick one box:

None, I am not a practitioner	0-2 years	3-5 years	6-10 years	11-15 years	16-20 years	20+ years

8) How much experience do you have working with children with cerebral palsy?
Please tick one box:

None, I am not a practitioner	0-2 years	3-5 years	6-10 years	11-15 years	16-20 years	20+ years

9) Please state any additional professional development, short or long award-bearing courses you have attended which helped you to support the development and learning of children with SEN and disabilities. Please indicate the extent to which these helped you to support children with motor difficulties by ticking the relevant box.

Course:	Very useful	Useful	Not very useful	Not useful at all	Not sure
a) _____					
b) _____					
c) _____					
None, I have not attended any courses <input type="checkbox"/>					

10) Please indicate the extent of your knowledge and understanding of the specific development and learning needs of children with cerebral palsy. Please tick one box only:

Very confident	Confident	Slightly hesitant	Very hesitant	Not sure

11) Here are listed some informal opportunities for strengthening understanding and developing practical skills relating to support for young children with cerebral palsy. Please tick the ones which you feel have helped you to work effectively:

1.	Practical guidance from experienced colleagues within the setting	
2.	Advice given by parents of the child	
3.	Advice from the child's therapist(s)	
4.	Guidance from the area SENCo	
5.	Home visit	
6.	My own practical experience with children themselves	
7.	Observing others working with the child	
8.	My own research about cerebral palsy	
9.	Visiting other settings where they work with these children	
10.	None. I have not had any of the above	
11.	Other, please specify:	

Please indicate which one of these was the most helpful for your work (if any): _____

12) In your view to what extent do the following strategies support the development and learning of these children? Please tick one box for each area.

		Very important	Important	Not very important	Not important at all	Not sure
1.	Changing the environment for easy access					
2.	Adaptation of toys, tools, equipment					
3.	Providing more time					
4.	Simplifying activities					
5.	Providing specific activities					
6.	Letting the child to learn by trial and error					
7.	Letting the child choose whether or not to participate					
8.	Providing continuous one-to-one support					
9.	Increasing motivation					
10.	Building confidence					
11.	Providing repetitive opportunities for practice					
12.	Giving continuous positive reinforcement					
13.	Telling the child what to do and how					
14.	Providing technology to enhance independence					
15.	Having consistently high expectations					

13) While recognising the varied impact of cerebral palsy for individual children, in your opinion which three of the above strategies are in general the most important for the development and learning of these children?

a) ☐ b) ☐ c) ☐

14) Again recognising the varied impact of motor difficulties on the development of individual children, in your opinion how important are the following areas for children with cerebral palsy? Please tick one box for each area:

		Very important	Important	Not very important	Not important at all	Not sure
1.	Playing individually					
2.	Playing with other children					
3.	Using hands at table-based activities					
4.	Moving about					
5.	Communicating with other children					
6.	Communicating with adults					
7.	Eating and drinking independently					
8.	Dressing					
9.	Toileting					
10.	Carrying out special tasks prescribed by therapists					
11.	Using specific equipment provided by therapists					
12.	Encouraging general participation in activities					
13.	Influencing behaviour					
14.	Dealing with medical demands					

15) If you had to choose, which three areas from the above list are in your opinion the most important when working with children such difficulties?

a) ☐ b) ☐ c) ☐

16) Are there any other priorities which you think are important to enhance development and learning of these children?

17) Any other comments to make about areas of development and learning of these children?

Thank you for your time! Your contribution to the research is highly appreciated!

Please provide your contact details if you would be willing to participate in further aspects of the research. Thank you.

Your name: _____

Position: _____

Email: _____

Phone: _____

PLEASE RETURN THIS QUESTIONNAIRE IN THE ENVELOPE PROVIDED.

APPENDIX D: INTERVIEW QUESTIONS FOR MANAGERS OF LOCAL-AUTHORITY SUPPORT SERVICES

1) About the interviewer, interviewee and the interview

- Introduction
- Purpose and procedures of the study and the interview
- Procedures, anonymity and confidentiality
- Interviewee's background, main roles and responsibilities within the service in relation to staff, children, their families and early years settings.

2) Key areas and roles of service within Children Services

- Main roles?
- People working in services? Their backgrounds? Key areas of their work?
- Workload: which children belong to your provision? Age? Diagnosis?
- Services: what are the objectives of your service in relation to supporting young children with CP, their families and early childcare and educational settings?

3) Procedures and processes for supporting young children with cerebral palsy

A) Referrals

- What are the procedures for getting into contact with families with young children with CP?
- Any challenges to establish this contact?

B) Early identification/assessment

- How do you assess the needs of children/families?
- Involvement and roles of parents and other professionals?
- Focus of assessment?
- Post-assessment arrangements?

C) Provision

- Frequency?
- Nature of support?
- How do you review progress?
- Challenges? Conflicts?

D) Statement of SEN

- At what age does the process begin? Initiated by whom? How long does it take?
- How are parents supported through statementing?
- Any challenges? Appeals? On what grounds?

E) Parental involvement

- In what ways do parents get involved with the provision?
- What are the common needs of parents? How do you accommodate individual needs/wishes?
- In what specific ways do you support parents in their upbringing of children with CP?
- Conflicts? Challenges?

F) Collaboration with other professionals

- In what ways is collaboration pursued within Children Services? With whom?
- How is inter-professional collaboration evident in the practice of supporting children with CP and their families?
- In what ways do you draw on the expertise of other professionals?
- How does your service complement support provided by other, non-educational professionals?
- What works well in multi-agency practice within your local authority?
- Challenges/conflicts?

G) Support for early-years settings

- In what ways do you support children in various early-years settings?
- How do you support the setting itself?
- What areas of early-years practice work well?
- What are the common challenges practitioners experience in terms of supporting children with CP?
- What practical and training opportunities do you provide for settings? How are these perceived?
- What are the most challenging aspects of working with settings?

4) Any other comments you wish to make about your service? Any questions?

Thank you for your time.

APPENDIX E: INTERVIEW QUESTIONS FOR PARENTS OF OBSERVED CHILDREN

1) About the interviewer, the interview and the child

- Introduction
- Purpose and procedures of the study and interviews
- Recording, anonymity, confidentiality
- How old is your child? Likes/dislikes? Favourite activities?

2) Early development

- How did your child develop as a baby?
- What were your key priorities for his/her parenting?
- What practitioners were involved with early support?
- How old was s/he when diagnosed with cerebral palsy?
- What were the circumstances of providing you with the diagnosis?
- What were you told at that time about cerebral palsy in general?
- What were you told about your child's development in particular?
- To what extent did this information help you to understand your child's condition?
- What provisions were you initially offered for your child?
- What areas of development and learning did professionals focus on at that time?
- In respect of helping your child at home, what specific things did you learn from this input?
- Have any professionals indicated to you what you might expect in relation to your child's development and learning in the longer term?

3) Current arrangements for support, childcare, education

- At home: how does your child play, move about, communicate with siblings and other family members, feed, sleep, dress, use the toilet, occupy himself/herself during the day?
- How do you go about helping your child with these activities?
- What are the current arrangements for childcare? How did these arrangements come about?
- What do you know about how your child is helped in nursery/school?
- In what ways do you keep contact with staff?
- What additional input does your child receive from other professionals? What the arrangements for this?
- What areas of development and learning do these practitioners focus on?

4) Priorities, aspirations for the future

A) Short-term:

- In your opinion which aspect of his/her development has come on well as the result of input from various services?
- In your opinion are there any aspects of your child's development which have not been addressed in any provision?
- Are there any specific skills or abilities which you would like your child to learn before starting school?
- To what extent are you satisfied with the input and support your child receives? What works well? What would you like to work better?

B) Medium-term:

- What type of school do you wish your child to attend? Why? In your opinion what will be the key concerns for your child when attending school? Why?
- In your opinion what should be the key priorities for your child's school learning?
- In your experience what sort of help will s/he need to succeed?

C) Long-term:

- What are your long-term wishes for your child?
- What kind of help will s/he need to achieve these?

5) Any other comments to make about your child's development and learning? Any questions?

Thank you for your time.

APPENDIX F: INTERVIEW QUESTIONS FOR PRACTITIONERS WORKING WITH OBSERVED CHILDREN

1) About the interview, interviewer and interviewee

- Introduction
- Purpose and procedures of the study and the interview
- Anonymity and confidentiality
- Interviewee's qualifications, professional background
- For how long have you been working in this setting? In what capacity?
- What is your previous experience with young children/with children with SEN/children with CP?
- What are your specific roles/responsibilities in relation to the target child?

2) About the setting

- Catchment area?
- Profile of the provision?
- Number of children on roll?
- Number of children with additional needs/disabilities?
- Who else works in the setting?
- How are roles shared in general?
- How are particular roles in relation to the child shared amongst staff?
- Any specific roles of the teacher/SENCo/TAs?

3) Admission, procedures for meeting individual needs

- Any specific procedures for admitting children with additional needs/disabilities?
- How did this happen when s/he was offered a place?
- How do you learn about children's individual/additional needs? How did this happen in relation to the target child?
- Who else was involved with the child's admission? Who else is involved currently in order to meet the child's needs?
- How do you monitor and review children's progress?
- What is your own and others' role in this process?

4) About the child

- Please can you describe the child at the time of his/her admission to the setting?
- Since then, what has changed in the child's participation and learning? Why have these changes taken place?
- What are the key objectives for this child's development and learning?
- Please can you give me an example of recent achievement? Why

did this come about, in your opinion?

- In your view what are the child's greatest challenges for his/her development and learning?
- What does s/he do well?

5) Practical strategies to support learning

- How do you go about helping this child in activities during the routine of your setting, in relation to general participation, also moving about, communication, using hands, free play, directed activities, self care?
- Have you made any changes in the routine of the group in response to the child's needs? Examples?
- Have you made any environmental adaptations in response to his/her needs? Examples?
- What strategies seem to be working well in relation to the child's participation in the routines and activities of the children's group? Why are they working well?
- Which areas of support do you feel have been less successful? Why?

6) Parental involvement

- In what ways do you work with parents?
- What are the specific benefits of such parental involvement for supporting the child?
- In what ways are you able to support parenting of the child?
- How are you able to accommodate parents' wishes/desires?
- What are the particular challenges of working with parents?

7) Collaboration with other professionals

- In what ways are other professionals involved in your work?
- How do you draw on their expertise in relation to supporting the child?
- What are the benefits of collaboration for yourself, for the provision and for the child?
- What are the drawbacks?

8) Are there any other comments you wish to make about supporting the child? Any questions?

Thank you for your time

APPENDIX G: OBSERVATION RECORD FORM

DATE:	SETTING:
CHILD:	AGE OF THE CHILD:
DESCRIPTION OF CONTEXT:	

ACTIVITY	EXPECTATION	INTERACTIONS and RESPONSES			THEME/CODE
		CHILD TO TASK	ADULT TO CHILD	CHILD TO ADULT	